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NATIONAL CONFERENCE

ON THE

EARLY AND PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT (EPSDT) PROGRAM

Denver, Colorado

March 17-18, 1981

P R O C E E D I N G S

Child Health Staff, Office of Standards and Performance Evaluation
Bureau of Program Operations, Health Care Financing Administration
U. S. Department of Health and Human Services

NATIONAL EPSDT CONFERENCE
Denver, Colorado
March 17-18, 1981

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P R O C E E D I N G S

OPENING SESSION - MARCH 17, 1981

DR. TIERNEY: Good morning, everybody. To open the Conference, I'm pleased to introduce Geraldine Trochek, the Deputy Regional Administrator of Health Care Financing Administration Region VIII, here in Denver.

MS. TROCHEK: Welcome to Denver and to the National Conference on EPSDT. For those of you who have visited Denver before, you're probably taken with some of the physical changes in the city. Denver is really emerging as an energy center in the Rocky Mountain West. With the renewed interest in natural resources and looking for oil to meet our energy needs, Denver is an exploding boom town.

When we talk of natural resources, what comes to mind is oil, but our children are really our greatest natural resource. Keeping our children healthy so that they can become productive members of society is one of our most important tasks. This conference is an opportunity for all to share experiences and gain new insights into EPSDT, and come away with a sense of how EPSDT will be shaping child health in the '80s.

Beginning in 1972, when all of the States were required to provide EPSDT, that was one of the most innovative approaches to health care service delivery. The Department of Health and Human Services (formerly HEW) and HCFA feel strongly that if EPSDT is implemented properly we can achieve the long-range goal of reduction, and hopefully prevention, of public dependency of a lot of needy youngsters on public care.

When EPSDT first became a requirement, I don't think we realized how many problems would be faced. Certainly you people are in a better position to tell us about the problems than the "experts" up here. Maybe one of the bases for a lot of the problems was the Medicaid program itself.

Medicaid traditionally reimbursed for services rendered to cure illnesses or injuries. The EPSDT approach, of course, was from a preventive, rather than curative, posture. That took a while to get used to, but we all recognized an obligation and opportunity to make EPSDT work effectively in trying to mesh together the private and public sectors to ensure a comprehensive health care delivery system. We have a lot of problems; that's a given. We also have a lot of uncertainties. We know President Reagan has proposed budget cuts, but we don't know what that will mean for EPSDT. I know there's much discussion. Yesterday I received a summary of the National Governor's Conference held last month in Phoenix. One of the Governors' recommendations is that the fiscal penalties associated with EPSDT be repealed. They believe that the penalties do not act as an incentive and focus on process rather than performance. I know we'll hear more about this.

Another uncertainty is the proposed legislation on a Child Health Assurance Program (CHAP). Considering the associated costs and the climate of cost-consciousness and deregulation, I am not too optimistic that CHAP will be passed. Despite the problems and uncertainties, we have amassed a lot of expertise that should be shared. We look to this Conference as an opportunity to share your experiences and insights. I trust we'll have a productive Conference. I want you to know the Regional Office is about half a mile away, but it's only a phone call away, and if there is anything that we in the Regional Office can do to make your Conference more successful or make your stay in Denver more pleasant, just let us know.

DR. TIERNEY: Before I make my brief remarks, I'd like to introduce the EPSDT-Technical Advisory Group (EPSDT-TAG) Chairperson, Vern Smith, of Michigan.

MR. SMITH: I have really looked forward to this Conference as a time when we on the TAG can have a chance to speak with you face-to-face.

Here is a notebook that includes 33 letters which many of you in this room wrote. In February we wrote the States, asking for comments and input as we enter into a period of sunset review on the EPSDT regulations. I view this as one of the significant things happening within the Medicaid program today. Certainly, when the Medicaid Directors get together there are few topics that occupy their discussions with any greater intensity than the EPSDT program and the application of the penalty and all the requirements associated with the program.

We have a significant opportunity to input into the development of revised regulations to adjust requirements in EPSDT so that the program can better achieve its goals. To those who haven't yet responded, we would like to have all of your input so that when we offer our advice on behalf of the States it will really be representative.

DR. TIERNEY: I want to welcome all of you, as the Director of the Office of Child Health, to what I hope is going to become an annual event. At this time of change, we were debating whether or not to hold the Conference, and we felt we should.

We wanted to increase the exchange of information between the States, the Regions and the States, and the States and the Federal government. We wanted to develop an overview and understanding of the history and the future of the EPSDT program. We also wanted to produce a body of knowledge on effective practices. We see this as a working session; where we can all learn from you. I think some positive changes are appropriate, and we need your help.

At the outset I'd like to thank the Regional Office for their hard work, and Frank Ishida, Gerry Trochek, Lauren Smith and Candy Salazar for their graciousness and hard work. I'd also like to thank Vern and the other members of the TAG. With all due humility, I think it's one of the best TAGs for HCFA. It's a very hard-working group of people who present some innovative ideas.

We're aiming for EPSDT to become the preventive arm of the child health program within Medicaid. There are a number of problems. I think that we are not taking credit for much of the preventive health care that is going on and that we're paying for, such as through the Children and Youth projects and private practitioners. It seems that there is an EPSDT program and then there is a "regular" Medicaid program. The penalty, the statute, and the regulation all contribute to that.

In an era of overall limited resources, we have to keep maximizing all our resources. Our program should aim at outreaching those children who are not getting any kind of health care. It seems that we outreach the kids who are getting health care and screened. Yet others are unimmunized and sick, and not getting the kind of health care they need.

In the past, we attempted through statutory changes to move toward reimbursing you for all of the child care you have been delivering . Without it, however, we can take a look at alternatives; that's what we're here for. Now we're trying to shift from the quality control kind of process toward a State assessment review; we're going to be talking about that in several of the workshops. We're going to try to do a thorough sunset review. Any of you who have not had a chance to get back with Vern, please do. We consider this very, very important. Vern and his TAG do superb work, but it would be better if we hear from everyone. Then, we'd finally like to move into an annual child health action planning kind of relationship where we can sit down and work with the States as to how best we can get care to those children who aren't getting any.

To keynote and start us off, I have the extreme pleasure of introducing a very old friend, Dr. George Silver. Dr. Silver has been one of the leaders in child health and health care for many years. He was born and educated in Philadelphia, received his degree from Jefferson Medical School, is a Diplomate of the American Board of Preventive Medicine. His memberships include the Milbank Memorial Fund Technical Board, the World Health Organization Expert Committee on Medical Care, the Medical board to the Maternity Center Association, and on and on. He has been a leader in the use of pediatric nurse practitioners, he was at Montefiore Hospital, and started innovative child health programs up there. He was a Deputy Assistant Secretary for Health under the Johnson Administration, and was responsible to a great extent for the development of the EPSDT program. He is now at Yale University. It is a great, great pleasure and honor for me to introduce a very dear friend, Dr. George Silver.

DR. SILVER: I don't want you to think that I'm the usual hired gun who runs in and says a piece that's only barely related to what you're interested in and runs away and doesn't appreciate the fact that you are part of a network of mutually interested and actively concerned people. Historically, I come right out of this program. I was part of the program analysis in 1966, on the basis of which the Section that provided for EPSDT was included in the '67 Amendments and became part of the Medicaid law. I left government in '68 and went to the Urban Coalition with John Gardner. There I became part of the group that formed the amicus curiae brief, on the basis of which the Department was forced to issue the regulation on EPSDT. It took almost three years from the time the law was passed until the regulations were written. By that time the local communities and State governments had discovered what kind of a price they were going to have to pay, and some of the difficulties that we're still wrestling with became evident. So, if I were to address you in any way, it would be "Fellow bureaucrats," or "Fellow agency officials." I'm part of the network that was involved in this development. I have this continuing interest. I really want to share with you some of the thoughts and ideas and, I hope, imaginative possible solutions that have come to me over the years that I've been trying to work within the framework of the child health program; sometimes in desperation, sometimes in hope. What I've got to say to you today will, I hope, be of some help to you in what you're trying to accomplish, and it will be of some help to me in what I'm trying to accomplish.

My feeling is that when a critical set of circumstances occurs, like a change of Administration (and everybody is concerned about what it's going to mean to his or her job), it's a time for us to evaluate what we liked or didn't like about the programs , and how we think they might be improved or modified. We should try to use the circumstances in which the changes are being made as leverage, something like judo, where you use your enemy's strength against him, and use the challenge of the time to try to improve the program. We cannot simply wring our hands helplessly over the fact that the money's going to be short and the opportunities limited.

Major interest in rationalization of child health services has shifted from consideration of program management to emphasis on collaborative services. At the same time, these forces have shifted from the Federal level to the State and local level. These two shifts are neither accidental nor unrelated. Revolution, concentration of authority and responsibility, including funding, below the level of the central government is a common development all over the world. The deconcentration is more than simple decentralization as described in earlier recommendations. It refers to severe limitation of the Federal role and expansion of the State and local role. This trend is now being facilitated by the new

Administration, whose campaign platform included this plank very visibly. The force for collaborative endeavor is also a result of the new Administration's campaign promise: less Federal role in policymaking; fewer Federal dollars in program development. Under the circumstances, it behooves the State agencies that have common goals to huddle together, examine their budgetary requirements, and determine which programs can be consolidated, which ones can be administered jointly, and which ones may safely be eliminated.

This is in no way to accept lesser quantity or quality of services, but rather, in design of the collaborative effort to preserve to the maximum the extent of services earlier provided, and to the extent possible, strengthen the programs in the hope of reach more, rather than fewer, people.

With regard to child health services, it is only fair to point out that the accretion of Federal programs has led to much duplication of effort, failure to establish priorities among service responsibilities, licensing and consultative responsibilities, and reporting needs. In many instances, no real knowledge of the dimensions of the problem of child health needs, number and location of eligibles, or even whether existing programs could effectively serve the eligibles, was part of child health planning.

The Inspector General in HEW reported last year on a child health delivery assessment. He found that EPSDT wasn't much of a factor in whether Medicaid kids got check-ups, and for poor kids not on Medicaid, no check-ups. Title V facilities gave very little care to such children, although this would be Title V's logical constituency. A bitter conclusion was that "Planning and coordination of child health care resources are lacking at the local level. Health Systems Agencies have not been encouraged to address this problem."

In other words, there was a lot to be done to make our child health work effective even before we were faced with the unpalatable necessity of dealing with reduced budgets and organizational changes. The need for collaborative effort in resolving the problems and issues was there, but agency rivalries and bureaucratic apathy stood in the way. Now, it's cooperate or perish!

A literature review of the publications in the field of maternal and child health for the period 1975 - 1980 dealing with health needs, availability of services and resources, and special problems of mothers and children confirms this. The evidence is that not much has changed in needs or requirements since earlier review; that poor and minority children and farm children are at a disadvantage, in that they need more, yet less service is available or obtained; that prevention is neglected.

The skewed distribution of resources and facilities for care have their continuing effect in maintaining the discrepancies in health status among poor children, minorities, and the geographically isolated. Furthermore, the lack of a universal eligibility to medical care skews the distribution in other ways -- a distortion in use of preventive services and lack of availability of such care; lack of appropriate utilization, or health and medical care services paralleling need.

Basic policies with regard to child health -- lack of universal eligibility, needs and means tests, State discretionary authority -- all hamper equitable distribution of services. Classical American patterns of practice: variety and heterogeneity of program ("pluralism"), specialization, fragmentation of programs, entrepreneurial nature of medical practice ("fee-for-service" and "solo"), individualistic character of the practitioners and emphasis on freedom of choice militate against rational universal provision of services.

Change and improvement will require better use of funds, more attention to organizational factors, more emphasis on prevention and more and better social intervention on behalf of children.

Child health services can be radically reorganized in such a way as to be beneficial to children in need, without added Federal expenditures, provided professional health workers will design different and more useful roles for themselves, and that agencies responsible will submerge their differences and their resistance to change. The success of the EPSDT program will depend eventually on the degree to which the entire system of child health care is reorganized and the degree to which professional roles change and agency collaboration takes place.

I don't think I need to go into lengthy rationalization of the need for reorganization of child health services, since your presence here presumes you recognize the need for some change. To my mind, no effort in child health improvement can be attempted as a solitary enterprise. To improve the program of delivery of EPSDT is, in my view, tied irrevocably to improving the child health program in its entirety.

I should say a few words to introduce the rationale for thinking in terms of <u>radical</u> change, however, and suggest a proposed scheme of action and the basis for the kinds and types of studies that may be needed to validate the approach, or uncover the obstacles to accomplishment. It is important to mark off problematic areas so as to be certain that appropriate feasibility studies will be undertaken and, from a political standpoint, what kinds of compromises may be necessary in implementation.

First of all, concern about the health status of American children needs no justification. A decision to deal with the obvious inadequacies in terms other than simple multiplication of effort does. To date, the two contesting approaches to improvement of child health services have really

dealt with only one approach, in different ways, of course. Successes have been described in which the choice approach is targeting: select underserved areas or groups and buy or provide the services to them such as children adequately served receive. The argument against this approach is that targeting is costly and inefficient, requiring wasteful resource deployment. The opposition says: let's reassign and redistribute resources into a compulsory system for all children. In effect, though, both are saying that the delivery system is satisfactory, but quantitatively insufficient.

My position derives from a reexamination of the delivery system itself. I believe that "medical care" or "health services," when used in connection with children, really represents three different things, demanding three different sets of actors and three different scenarios. Let me explain. Children's health needs include a variety of social factors that are not medical in origin, although they may have medical effects. Family stability, economic stability are such factors; included are things like good nutrition, maternity leave with pay, home help during the post-partum period, decent housing for the family, sufficient income to assure proper nutrition, clothing, and housing for the children. These are health promotion factors and derive from a social policy that protects families. It is not in the realm of medicine, nor do doctors do anything about this; it certainly is not in the curriculum of medical education that a physician is supposed to foster or pursue these ends.

A second aspect of "health services" is the preventive system. Physicians have customarily been the responsible professional group assigned prevention. But clearly this is not where physicians shine. Prevention is not stressed in medical education; it is not a lucrative aspect of medical practice and it is not professionally exciting. Nurses, on the other hand, do concern themselves with preventive aspects and devote a relatively large part of their curriculum to such concerns. They care about home visiting, and getting to understand about the family relationships that might be pathogenic or restorative; they are willing to go into the home to nurse sick people, to give injections, take temperatures and reassure worried families. They have no hesitation about giving immunizations, examining children in school, and doing the thousand and one things that add up to a preventive role. They do a lot of telephoning and establish liaison with social agencies and the courts. They are natural practitioners of prevention.

As for medical care, while doctors are not entirely willing to undertake primary care roles, they are happy to express themselves as consultants, taking on the difficult, complicated, interesting cases referred to them by primary care people, who may even be those same nurses who did the preventive work we mentioned above.

European experiences support this analysis. Nurses provide the bulk of the child health services in Scandinavia and Holland, and now in France.

Where, for administrative reasons, as in Britain, the nurse has been squeezed out of the preventive line, the system of care for children has suffered: immunization rates have dropped, examinations of school children have declined, home visiting has waned, and increasing numbers of "vulnerable" families, in the European terminology, find their way into social agencies.

There are other lessons in Europe as well. All European countries have programs of social care and health promotion, as outlined above. The size and depth of the programs vary, of course, but the relationship of this aspect to child health is clear, too. Where there are extensive programs -- Sweden, for example, with 6 months of paid maternity leave; or France, with a quarter of the family income of poor families from child and family allowances; Denmark, with a full rental subsidy for large families; and all these not income-related, but an obligation to the family and children of whatever income level -- in these countries the child health status, by whatever measure, is far superior to that of the children in the United States.

If these arguments would seem to support income measures as against health program measures, they do not. France had the best income support for families in Europe, and still has, since the beginning of the century. But it wasn't until they revamped their child health system and introduced the children's nurse and home services that the infant mortality rate began to fall. Some people argue that the Scandinavian countries are small and homogeneous and the other explanations are spurious. Holland is not homogeneous, although it is a small country; still, it maintains the same level of health among its minorities as in the majority. Ireland and Belgium are small, but do not seem to be able to achieve what Holland and Finland have. True, neither of these countries is as wealthy as Holland, but Finland is a poor country, and Finland has an excellent child health program and very low infant mortality.

Developing an American model along modified European lines would not require Federal legislation, although it would certainly require waivers by the Federal government of Federal regulations now governing use of Federally-designated child health appropriations. It would require, at most, State legislative action. Considerable spadework in the States would be necessary to establish exactly what ought to be done, and how. It would also be desirable that more than one State be set up as pilot models.

Even if one accepts all the premises implied or stated in the argument, why would State authority, responsibility, and administration be desirable? Any number of political science tracts over the years have demonstrated the ineptitude, corruption, and unreliability of State operations. In our own study, we were able to show that States can craftily undermine the Federal intent; deploy funds in such a way as to substitute for,

rather than supplement, Federal funding in defiance of maintenance of effort requirements. Minority groups recall with considerable bitterness the discriminatory practices foisted upon them in defiance of Federal law; a defiance still a visible aspect of State practices in education, employment, and public services. Why isn't a Federally controlled and operated system more desirable?

First, there is the larger view: government cannot simply grow to any size and still function efficiently. Size is unwieldy, difficult to supervise and monitor, unresponsive and impersonal. Bureaucracy is bad only insofar as it fails to be responsive and flexible. Size makes it so rigid that the necessary humanity is lost. Philosophically, we may be on the way to decentralization of all government activities, not simply deconcentration by moving offices, but moving authority. This Administration is clearly committed to devolution.

Then, it is abundantly clear from other experiences that the people who are served must be involved in the planning and administration of services - it may not be as necessary in industrial situations and production of goods, although that, too, is coming to be considered a perquisite of the workers and consumers, but it is absolutely necessary in the service arena.

Third, lack of supervision and ineptitude are not the unique monopoly of State governments. The deficiencies of State compliance are as much a result of Federal neglect as of State evasion.

Finally, the European experiences show that local control requires participation financially as well as administratively by parents, local communities, the larger governing bodies - countries or provinces or departments - as well as Federal government. This cannot be achieved easily through Federal management.

In the light of increasing interest in finding and treating handicapping conditions in children, arranging programs for "mainstreaming" children, and throwing greater emphasis on the teacher's contributions to health knowledge and health supervision, the role of the school nurse is crucial. Structuring a preventive role for a specially trained child nurse practitioner, which includes responsibility for school health services and family-related services for school children, fulfills the newer responsibility admirably. The approach pioneered by Mary Ann Lewis involving teaching of the teachers who teach the pupils about health and self-care and the like would certainly more easily derive from a breed of nurse-practitioners within a comprehensive preventive system than from the isolated school nurse, as currently assigned, without supervision usually, and certainly without a locus in the community or the teaching world of which she is a part.

I propose, therefore, a strong advocacy effort be mounted to create a social milieu - health promotion, if you will - along the lines suggested by the Carnegie Report of Keniston and his associates, to strengthen families, providing economic support and social services to restore the family's competence to deal with the ills and troubles of their children in today's world. This would be a stage of the program, however, not the whole of it. Kahn and Kamerman have demonstrated how important this is; my own investigations have persuaded me that this may be a necessary, but insufficient, approach to effective child health programming. Furthermore, as a political matter, developing the public interest group, establishing the Congressional beachhead, preparing the legislation and inevitable compromises and delays will make this an eventual, not immediate, goal.

The immediate goal should be the establishment of a comprehensive preventive service for children, based on State operation, Federally funded in part, separate from a medical care program and distinctly oriented toward the child, staffed and operated and administered by specially trained child nurse practitioners.

Reviewing the requirements for modifying and improving our approach to EPSDT, we can see immediately how such a program would energize and facilitate the EPSDT program. Whereas now our emphasis lies in coping with fragmentation and the decisions forced on us by multiple and disparate sources, varying agency concerns, priorities and regulations, let alone rivalries and antagonisms within and among the different agencies and levels of government, the recommended model is sensibly monolithic. Planning agencies, if they continue to exist, Title V agencies, school boards, Head Start, community mental health centers all have a finger in the pie. Various public laws mandate concern for the handicapped child at home, in institutions, at school. It's not surprising that the electronic calculators who dominate wings in both parties cast a cold eye on "bureaucracy." True, it was Congress that did it, but Congress gives, and Congress takes away. This will be the decade of the short dollar, and we're going to have to learn to deal with reality far less rigidly, with far less emphasis on the clearly identifiable unit on which the money is spent. We're going to have to have emphasis on the clearly identifiable <u>subjects</u> - in this case, the children.

On another tack, I'd like to take up the cudgels for the States. They may not have done as well as they might, or ought, in the past, regarding health services for children, but then, who did? Our state of mind and political orientation made it close to impossible for them to do anything imaginative or broad scale. The conservatives didn't want to let loose of any money for anybody - except Lockheed and Chrysler - and the progressives wanted the Feds to do it. Regulation was foisted on local units, and the Regional Offices tended to be graciously understanding when State agencies failed to comply or initiate or follow through. It was over 20 years from the time a State child health plan was supposed to be filed

before one State I know of filed one. But then, Connecticut never got around to ratifying the Bill of Rights until the 1950s. Unblessed, unsupervised, and largely ignored, it's amazing the State health departments got to do as much as they did.

We will, of course, need national standards, good reporting, and appropriate supervision. We need ombudsman-type programs with local input for our health - as with other service - programs anyway. It is not to say that State programs work well automatically; but that we need State-, rather than Federally-controlled, programs.

On the other hand, it should be recognized that very few national laws get on the books without there having been some State pilot efforts to lead the way: Social Security, Prohibition, Civil Rights all had State predecessors. Saskatchewan was the bellwether for Canada's National Health Insurance 10 years before the other provinces caught up. If we want a national health program we'd better get some State programs working at it, as Hawaii and Rhode Island are trying to. If we want child health programs improved we'd better get some improved State child health programs going. If we want to eliminate the waste and get EPSDT as a lively, active and successful program everywhere, we'd better start regenerating State child health services.

Children deserve better than we have given them. We know what needs to be done. There are several different options for change and improvement. Let's try them all!

In that recent literature review I quoted earlier, I concluded as follows: "It is clear that the needs of the poor, minorities, rural farm folk, deprived and disadvantaged, wherever they are, cannot be met without changing universal entitlement, changing social attitudes, modified staff arrangements, and parental education. We are beginning to recognize that fundamental change requires more than a little tinkering here and there. This is especially true of child health services, in which the structure is defective, and a massive overhaul in design, staff, content, and funding will be required."

I still hold to that. Thank you very much.

SHEILA SWAIN: I'm Sheila Swain, from Minnesota, and I couldn't agree with you more about the use of nurse practitioners and the role of nurses in preventive health. We are attempting to do this in Minnesota, utilizing nurse practitioners on a Regional basis and teaching the teachers, but we have encountered unending opposition from the physicians. We have a Statewide screening program which the Minnesota Medical Association is attempting to undo in the legislature. What strategy can you suggest in this era of declining physician income, especially among the pediatricians who are working with/the defined child population?

There is a maldistribution with the physicians. Certainly in the urban areas there is tremendous competition for the consumer health dollar or the public health dollar, and we have encountered increasing opposition.

DR. SILVER: I have two answers to that. They're not related, and neither of them may be effective. In the first place, there is a fairly strong dissident group within the American Academy of Pediatrics that agrees with this position, and there are publications from the Academy to justify this, and you would be well advised to try to work within the Academy. Now, Minnesota is not one of the Academy centers in which this dissident group is significantly involved, but Illinois is. I think you have to work with pediatricians at some level to try to recruit those who will actively cooperate. You can't work without the doctors, and sometimes it seems you can't work with them.

The other is the legislative view. At some point the politicians representing the public, the State legislatures, are going to have to go to the mat with the doctors. In the past when there's been more money available, doctors have always won. Politicians have tried to go to the mat with them. What happened was that the doctors would withhold their services, and States then had to pay more money. For example, when they cut back on payments to the pediatricians in Connecticut no pediatricians signed up for Medicaid. Then parents had to take their kids to the hospital, where it was $25 - $30 a visit. The State was cutting off its nose to spite its face, and lost out. I think the situation is different now. By emphasizing the nurse's role, if you can sell this to the State legislatures, and you may very well be able to, these doctors may work with you. I don't have any easy solution.

DR. CENTERWALL: I'm Siegried Centerwall from California. We have exactly the same problem, and I might add that Mary knows how strongly the Academy has been pushing a bill to recognize that the only good care for children is to be -- private--.

DR. SILVER: Well, you have an ally -- you have an ally in California that most other States don't have, and that's your State Board of Quality Assurance. Did they help you?

DR. CENTERWALL: The doctors are very powerful in California.

DR. SILVER: They're not powerful on the State Board of Quality Assurance. Governor Brown saw to that, I thought.

DR. CENTERWALL: But they don't decide what the legislature is going to do. We have licensing for nurse practitioners. There's no problem with that, but the physicians want more of the program going to private doctors.

DR. SILVER: If you define the nurse practitioner as being eligible for the same kind of reimbursement as the physician, you don't have any problem with that, do you?

DR. CENTERWALL: No, we have that automatically. If you wanted to create a program that actually gave the first level care to the nurse, it would be just fought right down to the line. It would never go in California.

DR. SILVER: I'd like you to try it, though. I think the State Board of Quality Assurance would support you. I'm not making any anti-physicians statement. I'm a physician myself, and my income would suffer in the same way. If they offered my job to nurses at the University I would be out of a job, too, and I would fight the same way. I understand the position. I'm saying that from your standpoint as a reimbursing agency you can agree to reimburse the nurse practitioner for that kind of work, and not the physician. I don't see how your program can suffer.

DR. CENTERWALL: I thought you were saying that doctors don't give the same kind of care, the same kind of health education, follow-up. If I were going to try to give my children the best of all possible worlds and start them out with a nurse who would take the interest, do all the follow-up, and keep in contact with all the public agencies and look after their health education, that would mean taking those visits away from the physicians, many of whom are suffering from a lower birth rate and increased competition.

DR. SILVER: My thought is that the health department, with the support and stimulation of the Federal agency, would set up programs which the nurses would carry out, and offer the services to the people in the community. The people in the community would take advantage of it. In what way would the doctors be able to stop that?

DR. CENTERWALL: They could go to the legislature and have our program reversed. Our legislation specifically mentions the use of the child's primary physician.

DR. SILVER: May I suggest that you discuss this with Beverlee Myers. California is one State in which there has been either an overt statement or an indication of willingness on the part of the overall health agencies to support this kind of activity.

MS. WALKER: I'm Virginia Walker from Mississippi, Dr. Silver, and I have a couple of observations to make. Two years ago the Mississippi legislature was the first State to approve direct third-party payment to nurse practitioners. That bill is up for sunset review next year, and the physicians are up in arms against its being continued. We have a real fight on our hands. Mississippi already had a very good nurse practice law that did not tie the definition of a nurse practitioner into a narrow framework. So this fight comes just when we think we're making real strides. We also have funded rural health clinics. One of the criterion for a

rural health clinic is that a nurse practitioner must provide 60 percent of the services. Those are in our very rural counties and, oddly enough, despite local effort and promotion, they are not that well received. I'm a nurse, I couldn't agree with you more that prevention is one of the strongest characteristics of our profession. But the public really does not see the nurse practitioner at this point, at least in rural Mississippi, as the entry into health care. And it's going to take them a long time to overcome the bias.

DR. SILVER: What counties are we talking about? Issaquena and Sunflower? They don't buy nurse practitioners, and there aren't any physicians -- ?

MS. WALKER: Sunflower County and the Greenville area is one of the areas where we're rather well endowed. Issaquena has none. No, I'm talking about the south and east central sections of the State.

DR. SILVER: Have you talked with North Carolina? They have a rural health program.

MS. WALKER: Of course. We steal their nurse practitioners.

DR. SILVER: Well, what I want to know is, why are they better accepted? What does North Carolina do different?

MS. WALKER: I've worked with Carolina people a lot. One helped us set up a rural health clinic, and we talked about ways of changing. He didn't see anything Mississippi was doing any differently than North Carolina, except that Mississippi is more rural.

DR. SILVER: I guess I have to pass on that one. I thought that North Carolina had all the answers.

MS. HUNT: We do. It's interesting that whenever there is a physician assigned on a full-time basis to run a rural health clinic, the office calls almost double. It doesn't take them long to find out that there's a real doctor there.

MS. WALKER: It's a matter of education, it's going to take years.

DR. SILVER: I would really suggest that you explore that, because from my experience in three rural places, North Carolina has an outstanding program. I've had students down there come back, and they're sold, they want to go work in North Carolina. I had a young woman last summer work in South Carolina with the same kind of acceptance. We had a student group do a study in Vermont. We don't have the problem of acceptance. I'd like to know what the difference is in Mississippi. I suggest that you get a grant from Exxon to study the sociological and anthropological reasons. What would the answer be?

MS. WALKER: Well, to begin with, the grant was given to the School of Pharmacy. Need I say more?

MS. SHERIDAN: My name is Karyn Sheridan. I'm in HCFA's Office of Legislation and Policy. I would be interested in finding out how you would operationalize the Federal funding aspect in your context here. You don't seem to be against Federal funding, but you want State administration. You don't seem to be against national monitoring and the development of standards. It seems to me what you're saying is that the categorical aspect of Medicaid may not be working, and that there might be a divisiveness in Federal child health programs. Would you be inclined toward the consolidation of Federal funding, say in a block grant approach? Is that what you had in mind?

DR. SILVER: Actually, that's what I had in mind, but I hesitate to say it that way because the term "block grant" has other connotations. I see a block grant as having limitations, boundaries, and not just simply laying the money out and saying "Anybody who wants it can have it." What you have to say is that it can be used only within a certain kind of program. You can design the program yourself for children, but you have to use the money within those boundaries.

MS. SHERIDAN: Would you support taking EPSDT out of Medicaid and combining it with a number of other Public Health Service programs in a distinct administrative entity?

DR. SILVER: I think I would not take EPSDT out, but take Medicaid together with other Public Health Service programs, and even with the Department of Agriculture's health program, put together whatever money is being spent, allocate a part to children, and ask the States to provide a design in which they will show how this Federal money will be used. The States would be matching not only State funds, but private sector funds as well. I'd like to involve voluntary agency and parent contributions. I like the idea of the Dutch, for example, who have societies where they pay annual dues for services to offset some of the costs.

MS. SHERIDAN: I guess my problem is that, because of the divisiveness and competition among the various Federal agencies, I don't see that happening unless you elevate the administration either to the Office of the Secretary, or even to the White House. I have a hard time visualizing how you're going to get them to cooperate.

DR. SILVER: No, I don't think that would be necessary. I think that HCFA is already the result of a lot of thinking in the Federal Government. It took almost 12 years before funding agencies could be put together. I think that the idea of consolidating funding would be through HCFA, and not through the abolition of existing programs and development of some higher one. When you ask how you can make it operational, how you would do it, I would say you have to get more input from

below. What is it that States can do now? That's what you have to find out. What is it that they'd like to do and how would it be different in the way they would get to use the money? It's one thing for the Feds to try to develop a plan for States to use, and another to find out what the States are doing now. Each State may be able to do different things. So grants would be made on the basis of what the State is doing, can do, or wants to do. The Federal government decides whether it wants them to do it that way before awarding them the grant. I don't think you can make an overall plan, divide the money up, and pour it down. I think you really have to get more information from below.

AUDIENCE QUESTION: It seems to me that it's all well and good to talk about consolidation of services, but until the Federal government consolidates its programs we're not going to be able to do anything. We're just responding to the various pots of dollars that come down to us. We have prevention programs in Medicaid, mental health, and alcoholism, all focused on kids, but that just promotes the duplication.

DR. SILVER: That's substantially what I was saying. What I think, and would like you to think, is that the States can, by preparing coordinated or consolidated programs of their own, use their political leverage to get the kinds of waivers that would allow them to consolidate Federal grants despite the problems. The answer that I've always received is that you can't do it. I think you have to try.

MS. MYERS: I'm Merle Myers from Colorado. It's really nice to talk about working together. When grants come down from the Federal government to various pockets in the State it creates a power fight. You're going to have a difficult time getting them to interface, let alone integrate.

DR. SILVER: If it was easy you would have done it a long time ago, right?

MS. MYERS: You bet.

DR. SILVER: I agree that there are rivalries at every level and that there's competition. The State, the Federal government, everybody has a vested interest. When the money comes down to different pockets and there are different administrative people responsible, I understand. But you can't ask the Federal government to do one thing when you yourselves are not willing to do the same thing in a continued operation. Everybody's involved. We're all victims and we're all villians. Everybody wants coordination, but nobody wants to be coordinated. Regulations are more easily modified than legislative mandates. Regulations are subject to the Secretary's waiver, legislative mandates are not, and the agency has to comply with the Congressional intent. In some cases, you can't expect the Secretary's waiver unless you get approval from a Congressional committee. The thing is, you have to try. You can sit back and say nothing can be done. There are all kinds of

reasons why things can't be done. I want to try in a couple of States to find out how this could be done. The thing is, how do you change it? If you think it's worth doing, how do you do it? If it's not worth doing, let's forget it.

MR. PARNELL: I'm Wes Parnell from Massachusetts. I operate at the local level, and I feel the need to say that as we look at the health care for children, family stability, and screening or delivery services there has to be some type of integration of services. We hear all the time why it can't work, and yet, it does work from place to place. It usually works at a local level, and where it works it's effective. But all of a sudden the incentives run out. There isn't enough money coming from the State, or there are some people who have to protect their territory. But it does work, and I agree with you, it needs to be tried at the State level somewhere. If we get some successful models it's where the payoff is going to be.

DR. SILVER: I know that Massachusetts has done a tremendous job with children in a number of areas, and I talked to Jerry Stevens on a number of occasions about what he did. It's not what he did, but it happened. And Connecticut tried to do the same thing and hasn't succeeded. Well, I think we've exercised the question long enough, and it's time for a break.

MR. LEEDS: As a national focus, and one for which we want some consistency and comparability, developmental assessment is new to the EPSDT program. Many States and others in the child health community have been actively involved in the subject for years, and we find ourselves trying to catch up.

We have committed ourselves to providing some information and guidelines on developmental assessment, especially since it's a required service now under EPSDT. For years the EPSDT program has really focused on physical health, but now we'll be dealing in a new realm. We'll be dealing in things involving the brain. A year ago when I started writing the guidelines, I remember casting about for some kind of guiding philosophy, some kind of overall help. I spoke with an eminent developmental psychologist and laid out our problems to him. He was quiet and thoughtful for a minute, then said, "This is a very interesting topic you've got ahead of you." He also said I should remember that the human brain was a miraculous kind of thing. It was something that starts working for us the moment we're born and the doctor slaps us on the behind, and doesn't stop working until we get up to speak in public. I've always found that very comforting.

I hope that by now all of you have received copies of our Action Transmittal containing the Developmental Assessment Guidelines. It was more difficult to issue than it was to write. It took about six months to get out after writing it. All of you who deal with bureaucracies know what that's like. We apologize for not having had it out sooner.

In preparing the Guidelines we consulted widely. I think we sent out about 300 copies of the two drafts that you received for review. Each reviewer has had one or two opportunities to respond to the draft, in either written or oral form. Many Federal agencies, professional groups, advocate groups, child development experts, and universities helped us. That's quite a lot of input, and we tried to respond to each.

We tried to put the best current thinking on paper. This was a tough assignment because there's a lot of knowledge, but there's not much agreement. We've tried to put forth a general approach that could be followed when considering developmental assessment under EPSDT.

We tried to steer away from calling for specific tests, and instead lay out a workable methodology. First, we stress that it's important to contact other State and interested groups: the MCH and the CCS programs; the mental health people; the educational community, both special education and regular education; developmental disabilities programs; university-affiliated programs; university research organizations; and professional groups.

Further, we think it's useful to bring together the varied providers that you'd like to work with to help you decide what information you want to collect on each child and the elements of the screen. Then you have to decide how to screen and how you're going to collect the information you want.

The important thing to remember is that we're talking about two steps, a simple screening, and only them a formal assessment, if needed. We're not talking about universally performing scientific, heavy-handed examinations of each child, or running each child through a battery of tests. Rather, we have tried to outline the kinds of things to look for, the simple ways that one could get into screening a child for a developmental assessment.

If the initial screening shows that the child is within what you consider accepted parameters, and that can vary from State to State, fine; you've done what the guidelines call for. On the other hand, if there's the glimmer, the suspicion, the potential for a problem, that's when we can use specific tests and instruments. We at the Federal level do not want to advocate a specific test or instrument. There are simply too many, and I don't think that we have a reliable way to recommend one over the other. That's a buck we pass to the State, under what we call flexibility. I think the same information that we could collect would be available in each State, and I think we're more comfortable in leaving those kinds of decisions up to States.

We have eight panelists who are going to keep their remarks brief. Sandy Axelson is from the Florida Department of Health and Rehabilitation Services. Martina Brown is from the Georgia Department of Medical Assistance. Jim McKittrick is from the Pennsylvania Department of Public Welfare, and Dr. Siegried Centerwall is from the California Department of Health. Dr. Nancy Stone is with the American Association of Psychiatric Services for Children which, under contract with our office, came up with quite a bit of information and useful publications. For example, "Developmental Review in the EPSDT Program," was a good piece of work.

Dr. Vito Cessa is from the Boston Children's Hospital Medical Center, and will be discussing some clinical issues involved in developmental assessment. John Shwab is from the Bureau of Community Health Services, and will talk about Public Health Service programs and how they can help. Dr. William Frankenburg, from the John F. Kennedy Child Developmental Center here in Denver, is the father of the "Denver Developmental Test." He's going to be talking about constraints and philosophical issues.

MS. AXELSON: Florida is organized as an umbrella agency. We have the Department of Health and Rehabilitative Services, which is the State agency that administers Medicaid through 11 HRS districts. The EPSDT program is entirely State-administered. Our county health departments are under the Health Program Office under the Department of Health and Rehabilitative Services.

Florida has always had a developmental assessment component. It has not been very detailed, but we have had it in our screening package since the inception of the EPSDT program. What we do is outlined in our screening guidelines to providers, who are primarily the county health departments. Until October of 1980 they were our only screening providers for children's medical services. After that we opened it up to private providers, clinic physicians, rural health clinic nurse practitioners, and neighborhood health centers; and we do have some migrant health clinics in Florida, because we have a pretty big migrant population.

In our screening package we ask providers to obtain information from the parent or the person who has knowledge of the child about the child's development, such as how the child is doing at a certain stage. This is mainly taken during the health and developmental history stage of the screening. We are asking them to observe behavior.

We find that most of our providers observe behavior during the entire screening examination. We ask them to talk with the child, to see how the child is doing in school, if the child is in school, to see how they're developing, how they're working, playing with their friends, can they dress themselves, do they feed themselves, and so on.

We ask them to observe the eye-hand cordination. They pick up a lot of this during the vision portion of the screening package, checking such gross motor functions as walking, hopping, climbing. Some of the health departments are asking the child to climb - "Climb up on this chair, climb up on this stool for me." We ask them to check speech development and vocalization through self-help skills or behavior development. In some cases we have told them they can do a Denver, but we are not requiring it in all cases.

It's a little difficult for our screening providers to say: "we checked developmental assessment." We have a little portion of our screening package to fill out, but they do check it and make comments on it. That is kept in the client files and in the provider files in the Health Department.

I've found that county health departments are really excited about spotlighting developmental assessment. They feel they've always done it, but they want some better guidelines. They do plan a training session in about six months, a Statewide training session with the nurses to say: "this is what you should do for developmental assessment to develop some kind of Statewide standards."

Before I came down here I also talked with the Florida Pediatric Society. It's easy for us to sit there and say: "we do this and this and this," but until we find out what they really want, we're not sure. The Pediatric Society apparently feels that they have always done a developmental assessment on all screening through observation and talking with

the parent. They do not indicate in the client records that they did developmental assessment per se, except when they make a referral. Private practitioners do not generally do a Denver or another type of test unless there is a referral.

Some of our health departments are trying to do a Denver on the younger children right away, particularly at an initial screening. We find some problems. For example, they feel our guidelines are not clear. We tell them to check eye-hand coordination. We don't instruct them to do it as a separate portion of the package. We do ask them to check on the claim form to make referrals for it. Apparently, we need to define developmental assessment further for them.

We find that our providers do not use a standardized test at all times. As with the HCFA guidelines, they do not want us to dictate to them what test to do at what time. They feel that a standardized test should be done if they do not know much about the family, if it's an initial screening, or if there is a referral.

We experience some problems in clarifying when to make a referral. Because they have so many clients going through the system at one time, they often don't know the client as our private practitioners will, and they're not sure if it really is a problem, or if the child may be reacting to a crowded room, or may be nervous because of the screening examination.

In Florida, we're finding that we require developmental assessment, but in some cases may not reimburse for the services of developmental assessment. I think all States have that problem.

When the Florida Pediatric Society reviewed the guidelines for me they were concerned about specific monitoring for the developmental assessment. Pediatricians say they do a very comprehensive developmental assessment through observation, but don't indicate in the client's records that they did developmental assessment. It's on our claim form, but if we were to go and review the records from our private practitioners, how would we know they'd done a developmental assessment? They're slightly concerned about our requiring them to indicate in the client's record what they did, or any details about it. I think it goes back to the problem that all States have, even with the screening rate we're not paying a tremendous amount of money, we don't want to hinder them with a tremendous amount of work.

I'm going to sit on a committee with the Pediatric Society of Florida in the near future to develop some comprehensive guidelines. We believe we are in compliance with the guidelines, but we feel we need to give a little more direction.

We want to try to work more with schools. We feel this is probably your biggest point with the older children. We want to try to get the

training around the State. We're lucky in that we have to do some comprehensive EPSDT training by July because we're coming out with a revised manual, and I want to have standards developed by that time to discuss with all providers.

MR. MCKITTRICK: Developmental assessment was a departure from some of their other guidelines. We're in compliance. The only thing we disagree with is establishing training programs because it's not the role of the State Medicaid agency to train physicians in their art or craft. I think that's the place of the medical school and continuing education programs set up by medical societies. The State has traditionally never been in that role, and never considered setting up such a program.

What we have done in screening is under the rubric of quality control: what we expect you to do for the money. If you're not sure, we're offering you advice from our contractors to help you avoid being removed from the program. That advice was not a formal education program on developmental tests.

Since we have two contractors, one for greater Philadelphia and the other for the rest of the State, we have a sort of check and balance. When we compare statistics and findings they match up well with the developmental referrals just as for other referrals. The two-county area provider has more small-town rural providers and a different type of population compared to the population in Philadelphia and surrounding areas. The institutions that do most of the screening in Philadelphia are large medical schools, very sophisticated medical people, as opposed to the country doctor types in the middle of the State.

Our results are similar. We figure that we've done a good job at quality control. Everybody's giving us what we want and we're happy with it. We published developmental assessment in the regulations and there was very little comment about it. We had a couple of groups come in that were involved in definitive child psychology and child developmental programs. They, of course, were looking at it from their perspective and wanted more specifics. We said no, we're a screening program.

Pennsylvania has many developmental programs: a Governor's Developmental Disabilities Council, programs under education, mental health and health. We cooperate with all, and are members of the Developmental Disabilities Council, which has a book of resources for Pennsylvania children, including EPSDT. Teams of all kinds of people involved in children's problems are set up around the State. They meet periodically to discuss particular cases on particular children in a particular area. These provide input to EPSDT via providers and social workers in county offices. One of our guidelines to the physicians on testing results covers referrals and resources. In addition, when going into an area and rounding up screening and treatment providers, we ask what resources they use. We prepare booklets listing specific resources to give to each

provider and each county office. We do this for everything from eye care to heart surgery, and include developmental areas.

According to physicians on our advisory committee, the problem with developmental assessment is not with the doctor identifying a problem. The problem is, where do you send the kids and who does what? That is the problem with your average physician. We tried to overcome that by making these lists available resources.

I don't think we've been entirely successful. We still need more of a breakdown as to what area is the best. That is one of the things we will be continuing to do in the program. We think we've solved a lot of the problems. We incorporated our usual delivery system for screening, and we use the same quality control and training procedures for developmental assessment as for every other part of the package. The hard part is wading through all of the different theories and approaches to handling developmental assessment, and since we weren't in a position to really make accurate judgments, we picked the one that was easiest to administer.

DR. STONE: I worked on the American Association of Psychiatric Services for Children project which produced developments and recommendations, which then evolved into a form of approach. When I began, there'd been a conference that had developed the philosophical approach. Then we worked for another 2-1/2 years trying to operationalize it. Besides the primary care people that have been mentioned, we brought in the people who were doing the intervention down the line: child psychiatrists, psychologists, occupational therapists, physical therapists, speech therapists and social workers.

I'd like to tell you a little bit about some of the things that happened along the way over this period. First, we started off with the mandate to identify instruments which could be used to screen for mental defects. The concern was with the apparent intent of the asssessment, with what kind of mandate we should have. The first year the recommendations were made quite specifically that this be modified to a mandate to deal with some sort of system to support the development of children.

As many people have mentioned, we felt that the term "mental defect" is stigmatizing. It causes anxiety to parents, it may harm the child, and is not a useful term. The recommendation then was made that in the expectation of limited resources (and little did we know how prophetic we were) the most unserved population was the birth to five-year-old child. We felt that developmental assessment of the school-age child could be done in a school setting where the child already was, where people and teachers have been demonstrated to do a good job. The interagency agreements were probably more appropriate for the school-age child, rather than developing a parallel system.

We then went on to the issue of selection of instruments. Here there were other concerns. One, the idea of using an instrument, implies that

there's a clear demarcation between normal and abnormal development, which can be identified through the use of a specific screening test. Everybody agrees there are some children who clearly fall outside of the range that we all think of as normal, but most of the children receiving these assessments are in a kind of gray area. The children who fall clearly outside the range of normal are usually going to be picked up on a physical exam in the first place.

How to deal with this gray area of children whose range may be questionable? Maybe they're delayed, maybe they're not. A mere pass-fail answer on a test does not offer enough information. The question also was raised in California whether the standardization of some of these tests discriminated against minorities unfairly. Some studies demonstrated that the Illinois Test of Psycholinguistic Abilities discriminates unfairly against children with an Appalachian dialect. Discrimination is sometimes brought up regarding children who speak a black, non-standard dialect. Some people in the Southwest felt that the Hispanic families are not as into self-help skill development at an early age, and will fail self-help items simply because there's a cultural difference in expectations.

Other concerns were that very young children are intimidated in the test setting, and may fail to demonstrate behaviors they have mastered and use in their own home environment. If the screening instrument is used alone, these children may be falsely identified as having problems of some type, increasing parental anxiety that the child may be stigmatized. Such concerns are often self-fulfilling. There has been increasing research that in a family which has the potential for child abuse, the child who is perceived as different is the child most likely to be abused.

Then there was the issue of program costs, the concern that the comprehensive assessment would be more costly than the assessment within primary care. We believed that the acceptance by HCFA of the use of screening instruments alone increased the risk that, in order to reduce costs, a technician might be given the responsibility for administering a simple test, leading to quick, unproven judgments.

Today I haven't heard much about what may be accomplished with parents when assessment takes place in a primary care setting. We felt that informing the parents that the child had failed a screening test didn't give parents much information about the type of problem, or what the parent might be able to do to help the child.

We felt that there are social policy implications in Federally funded programs that led us to question the wisdom of the Federal government saying that the children who do not meet the behavioral criteria of a specific test are to be identified as abnormal. These same social policy concerns precluded the use of any formal assessments of the home situation, although there have been a number of studies which show that

one of the risk factors relating to later problems is the inability of the family to be emotionally available to the child.

As to our conclusions, first, there was general agreement among the professionals with whom we worked (many of them developers of well-known tests) that specific screening instruments should not be recommended by HCFA. Screening should be accomplished through a structured clinical evaluation by a professional who was trained to evaluate the child's age group and culture. Methods to be used should be left to the discretion of the providers. The health and developmental history that many States do should include information which came from parents, either by interview or by questionnaire. Information recorded regarding the child's temperament, also a risk factor, including the child's usual functioning in the natural environment, helps the provider understand behaviors that the parent deems culturally appropriate: elements of which the provider may have been unaware or in disagreement with. Also, someone should ask about the parents' feelings and any concerns about the child's functioning.

Second, information should be obtained from the child by the professional, who observed and, where necessary, recorded it, either at one time or throughout the evaluation. Recording should be systematic, and not "okay - within normal limits." The result is a recording of the most mature behavior demonstrated by the child in each of the separate developmental domains. Again, the method for arriving at this determination could be clinical judgment regarding whether the child met milestones of overt behaviors, or there could be a standardized screening test that was deemed appropriate to the population being observed.

Third, from visiting EPSDT sites, we believe that record forms should provide information to the parent at the same time as providing information to the provider. Instead of just reading down the columns that the child either is or is not within criteria, you also can read across, noting that the child is at a certain point. For example, the child walks without support, and the next thing the child is going to do is stand on one foot with slight support. This provides information to the parent and gives you an opportunity for brief, but sometimes effective, anticipatory guidance.

We observed nurses using such a form and saying, "Over here, at the age of five, when the child is sent to school, it's going to be very helpful to him if he can do these things." They did not say that a child was abnormal, but described skills helpful to the child when entering school, e.g., self-help or holding a crayon. A child can be expected to progress more readily in language skills if he can talk a little. I think that in Minnesota some of the nurses were using the Portage curriculum developed out of the Handicapped Children's Early Education program. That's a resource which wasn't listed in anything I've seen. There can be a lot of anticipatory guidance to those children who may be in a slightly questionable range, but not delayed enough to warrant further referral.

Fourth, the decision regarding additional, more comprehensive and time-consuming assessment by appropriate specialists should be based on all information: the parents' belief that the child is meeting their expectations as well as the professional's. Further, we recommend that the outcome of the primary care evaluation of developmental status not be recorded in the form of a diagnosis, and that States not require diagnosis of developmental status as a condition for reimbursement of the primary care provider. The screening report can note whether additional developmental assessment is indicated for the purpose of determining whether the child is in need of assistance not available in the current environment. We avoid the issue of normalcy by looking at the child's needs. Obviously, a child can need assistance when the parents are not functioning well or not providing the developmental support that all children need. Sometimes a child needs assistance because he has a handicapping condition which requires a special kind of parenting. Sometimes the assistance is needed because the child has a neurological problem requiring direct intervention, such as special exercises.

We felt that if additional evaluation is indicated, the child should be referred to appropriate resources. Here, again, is a gray area of children who may or may not be a bit delayed, and the State should consider referring these children back to the primary care provider after a period for a second evaluation. At that point the judgment could be made whether the child should be referred on for more costly and time-consuming comprehensive assessments.

Finally, we recommended that attention be paid also to developmental assessment training and continuing education of primary care providers. It's been my experience that the literature that's come out on the many things that can be done to support the development of handicapped children often has not made its way into the literature crossing the desks of many primary care providers every day. We felt that it was important to let people know what can be done. Sometimes this tips the scales in terms of whether you refer early or whether you hope that the child will pull out himself.

MR. SHWAB: Acknowledging that the Administration's intent is to collapse or consolidate a number of health programs into a single block grant, don't let anxiety about reductions or consolidations slow you down. If anything, this may be a better and more appropriate time for you to get together with other programs with a view to assuring that children and their health do not get short shrift. We need to be prepared, perhaps more than ever before, to be advocates for children, and in a bit different way than we've been in the past.

The Office of Maternal and Child Health has a number of programs that relate to EPSDT. Also, in the Public Health Service there are a number of other primary care programs on which we have placed certain requirements related to EPSDT over the last year or two. For example,

we're asking all of the 900 community health centers and rural health centers across the country to become providers of EPSDT. We realize that some States do not provide clinic services as a basic service. Also, we are asking health services projects to assure all children served are involved in continuing health care. These priorities have been defined in Action Transmittal 80-80, issued jointly by HCFA and the PHS to guide better relationships between EPSDT and MCH and CC programs.

The basic message is to encourage the establishment of a "developmental assessment plan," above and beyond the use of procedures for either screening or assessment. Every State program should devise its own developmental assessment plan, with certain ingredients. First, the plan probably should be based on a developmental approach to early identification, a concern for the promotion and early detection of developmental problems, that begins with a focus on risk factors during pregnancy, newborn, and infancy. Second, the plan should demonstrate concern for potential risk factors which may lead to problems of growth and developmental process at all age levels. Third, developmental assessment should be included as an integral part of every child's individual care plan, whether it's an IEP under P.L. 94-142, SSI, or a basic health care plan by a private practitioner. Fourth, that care plan should be integrated into a plan for providing continuing care for children.

DR. CENTERWALL: We encountered tremendous resistance to doing developmental assessments, any kind of screening test, in California. When it started, the Child Health and Disability Prevention program was interested in the potential for picking up early signs of physical and developmental problems in children. The State legislation that initiated EPSDT under Child Health and Disability Prevention also required for the first time a school entrance examination for every child entering school. The program felt that it was appropriate to implement developmental assessment, requiring Denver Developmental tests for all preschool children and the school entrance exam.

The reaction was both from welfare and civil rights people and providers. Many physicians were not prepared to spend the time to do testing. The result was that the task force put together in 1975 met quite a few times, and decided to eliminate the Denver test. Apprehensive of labeling children, it recommended that a developmental history and a comparison with milestones be used by the examiner. We have minimal developmental assessment, without specifics.

When the new Federal guidelines came out, I think we were minimally in compliance. We did require assessment of development, but implementation was probably uneven. We have different kinds of people in different settings doing it: private pediatricians, family practitioners, nurse practitioners, in both schools and public health department clinics. There is some evidence that people forget what normal milestones are and do not screen very well for development or signs of psychological problems.

We then decided to set up a new Task Force in conjunction with the CHDP advisory group, the State Child Health Board. The Board already had representatives of providers, parents, school nurses, county health officers, and advocates. We added clinical and school psychologists, child psychiatrists, the American Academy of Pediatrics, the California Medical Association, and others. They took another look at it. Many were aware of what had gone on before, and they decided to try to define what a developmental history should be at certain age levels, to give some structure to this mandate.

A draft guidance has been approved by our Task Force, but not yet by the Department. One of the big concerns was about being culturally sensitive. This was dealt with by emphasizing the role of the family. Sometimes the most important thing with a child of another culture (we have many Southeast Asian refugees, for instance) is to find out how the parent views the child. Is this child doing about the same as expected in comparison to other children they know? Then there are milestones, things that the child should be doing by a certain age. It's a 90-percent-pass kind of screening/developmental history. I don't know whether it's too lenient and we're going to miss a lot of children with problems.

The draft also incorporates more level-two assessment. Now, people do initial review at the primary health assessment, with recourse to refer for diagnosis and treatment. This concept recognizes a first screen, followed by a second level of assessment which is still not diagnosis by a pediatrician or someone qualified to further test a baby or school-age child.

Level three is the definitive diagnosis and treatment stage. We will train people to understand the different levels, and will also build referral resources. Some people are trained to do Denvers, but not enough to cover the State. We are working with our Department of Developmental Disabilities, which is accustomed to referring children with severe disabilities, and doing complete, expensive workups. We are also working with the Department of Mental Health to put some structure in the process. We hope involved people will feel comfortable to refer to another level of assessment, and not move to diagnosis right away.

MR. MCKITTRICK: At first, developmental assessment was a stepchild of the screening program in Pennsylvania. We really didn't go into it, we were too busy setting up our overall screening program. Basically, we used any kind of screening provider as long as they related to a physician who understood what was going on. They all use a uniform screening package. Every provider is approached by one of our screening contractors: the Philadelphia Health Management Corporation in the five southeastern counties of the Philadelphia area, and Automated Health Systems, Incorporated, for the rest of the State. The contractors explain the program to the providers, how to do the paperwork, and how to

do the test. They also do quality control, going back periodically to see what's going on. They interview the people: are they doing the test right? Are they recording things right? We had set that whole program up, but not really embarked on developmental. About 1976, when we had already established guidelines for hearing and vision, we decided we'd better start looking into it.

We tried the approach of bringing in knowledgeable people. We brought in school psychologists, who suggested taking questionnaires into the classroom. Information received from home and teachers would be entered and the form sent back to us, and somehow we'd filter this all back to the doctors. We dismissed that as cumbersome. We next brought in a consultant from a prestigious clinic. He suggested a scheme whereby children would read lists of sounds and we would tape-record them on cassettes and mail him the cassette and he would tell us what was wrong. We dismissed that scheme also. We had some consultants within our own department, from our Children and Youth and Mental Health agencies. One was big on "pre-delinquency." We said no, we don't want to label people. So we thanked them, and are moving ahead on our own.

DR. CESSA: I'm Vito Cessa, a Pediatric Fellow at Children's Hospital in Boston under Dr. Melvin Levine, Chief of Ambulatory Pediatrics. Dr. Levine has had extensive experience working with children on developmental and learning problems. I have been the medical and developmental consultant to an EPSDT pilot project, the Lawrence Children's Health Project. This project design is markedly different from the previous discussors' projects because it's school-based and deals with school-age children. We were referring back to the school-based, as opposed to outside, resources, and we referred to outside sources when indicated. I would like to talk about how these developmental assessments were incorporated into the Lawrence Children's Health Project and EPSDT screening, but first, some informal background regarding educational philosophy of the last 10 to 15 years.

During the late '60s and early '70s it became evident that many school children were experiencing academic failure for reasons other than limited cognitive ability, lack of motivation, or otherwise bad parenting. Terms such as "learning disabled," "dyslexia," "visual perceptual motor integration deficits," "minimal brain dysfunction," and "hyperactivity" became commonplace. Some children benefited greatly from being properly identified as having such learning problems, but often these terms were used loosely and indiscriminately. Many children still go unidentified, and others are inappropriately labeled.

By the mid-'70s it became increasingly clear that our nation's schools contained a substantial number of children with what could be termed a high incidence of low-severity handicaps. These children might have peculiar developmental profiles which incorporated specific areas of strength with areas of weakness. These areas of weakness were inhibiting their

learning and needed to be identified as problem areas so that they could be remediated. Areas of strength were to be fostered and used as a means to preserve self-esteem in these children at notable risk for self-esteem from repeated school failures.

About eight years ago Dr. Levine and Children's Hospital became intimately involved with the Brookline Early Education Project, a long-term prospective study of children designed to look at the natural history of such high-incidence, low-severity handicaps, as well as the physical predisposition and effect of intervention. The results of this study are just now beginning to unfold. During the planning and development of this project, several developmental assessment tools were created. It was hoped that such tools would provide a description of each child's strengths and weaknesses. Over the last several years these developmental tools have been used at the project and the hospital for both research and clinical purposes. In conjunction with other projects, several examinations have been developed that span the ages between three years and adolescence. The examinations require between 45 and 60 minutes to administer and require training in order to insure reliability.

Areas typically examined by the instruments include neural maturation, temporal-sequential organization, visual-spatial orientation, auditory language function, fine and gross motor function, and memory. Approximately five to ten minutes are spent testing each area. The examiner is also asked to observe and make some judgments about the child's potential skills activity level and behavior. This is important in order to help identify the child who may be having one or more constitutional or emotional problems, and who would be helped by further evaluation, counseling, psychotherapy, or medical intervention.

At this point I would like to share with you some aspect of the Lawrence Children's Health Project experience in incorporating developmental assessments into an EPSDT project. Approximately 15 months ago we began administering our developmental assessments to all children attending our initial target school. For children attending bilingual programs, assessments were administered by bilingual examiners who could switch between English and Spanish as needed. Approximately 320 examinations were given to all children enrolled in the program. A brief, two-page teacher questionnaire was completed by classroom teachers on each child. Sometimes special education teachers were called upon to help complete these forms. These teacher questionnaires served as an index of school performance. Based on these questionnaires, each child was put into a category of need.

A look at 224 first- through sixth-graders who received the developmental assessment revealed that approximately 35 percent of them had performance consistent with being at risk of school problems. This meant that two areas were delayed. Criteria for such decision-making was based on the clinical and research experience, with some modifications made for language, given the high incidence of Hispanics in our population.

The next point of interest is that the children designated by the teacher questionnaire as having performance problems (about 117 out of 224, or 55 percent) were felt to be actually developmentally at risk via our developmental assessment. We needed to look further at the remaining 45 percent to see why they were failing in school, but it did not appear as a developmental issue. Of course, our developmental assessment could have been not specific enough, or they could have been failing for attitudinal problems, socioeconomic factors, or cultural differences. What was most impressive, however, was that only nine children of the 224, or four percent, were felt to have developmental problems by this developmental assessment, but were not flagged as having academic difficulty.

These results led us to believe that we could utilize a refined teacher questionnaire as a pre-screen to identify children that needed a further developmental assessment. We could use developmental assessment not as a first-line screening procedure, but as a tool that would help us obtain further insights into why at least half of the children were having school problems. In other words, the developmental assessment became a mini-diagnostic tool that could potentially give us important information.

This led to our evolving the developmental screening process. The initial step is a pre-screening process with the teacher questionnaire. Parental history and informal impressions by the caseworkers who were taking the health and developmental histories were also utilized in making decisions regarding the need for further developmental assessment. Once a decision regarding the urgency of a child's needs was made, he or she was given a developmental assessment. It was forwarded, and the results recorded. Feedback to school personnel is given in aggregate form by our project's educational specialist who is familiar with developmental issues. She acts as a liaison between the project and the school. Her role is to interpret the developmental findings for the school by giving feedback to each teacher regarding the developmental profiles of children in his or her class. The educational specialist also gives workshops to school personnel and has dispersed various types of printed material regarding developmental and educational issues and regarding suggestions for remediation of children with such problems.

It is hoped that through such feedback classroom teachers will receive insights and learn useful techniques and strategies that would make them more effective educators. For some children, such positive effects may spare school systems the expense of more sophisticated special needs instruction because of their resource remediation periods.

In summary, our experience at Lawrence Children's Health Project has shown the viability of using a pre-screen tool as an efficient means of limiting the need for more intensive developmental assessments in the school-age populations. In some ways the developmental assessment has become a mini-diagnostic tool whose results, when shared with the school, may improve a child's performance, while at the same time decreasing the need for more extensive and sophisticated special educational services.

DR. FRANKENBURG: I'd like to welcome you, not only to Denver, but to the area of child development. I started in this field in 1964 when few people were interested in this field. We heard what many physicians are saying today; namely: we know all that stuff, and we can identify those kids. That's hogwash. The reason I say that is that we've been at this now for over 13 years; and we've had the physicians, who come to all the conferences, do all the latest, newest things, and we found that when they did screening in their offices they really blew it. You'd be surprised how many retarded children were not being identified by these physicians.

Since that time we've learned a lot. Now I'd like to show you a slide tape show on our view of what screening is all about. It contrasts with some of the other things you've heard. You're going to have to decide in your own minds in your own State what philosophical approach you're going to take: what are you trying to do, and why are you trying to do it? How is it going to help the child? When we started out we had the same problem you're facing now, the question of what is development? Is it temperament, or hearing? Is it speech, or is it sex development?

Our orientation is a sort of public health approach. I think you need to ask yourself a question that Dr. Wilson from Great Britain's Ministry of Health asked about the ethics of what we do. He pointed out the difference between what you, as a physician, would do if a patient presents himself or herself in your office. You're going to do some things that you are sure will help the patient. You may, in some cases, do something you're not absolutely sure is going to help the patient, but you try to do your best. That's what the patient expects.

That contrasts with screening. Screening is perceived as a secondary form of prevention. Primary prevention includes immunization. Secondary prevention includes early identification to prevent something happening down the road. Dr. Wilson's point is that if you launch a public screening program, you're implying to the public you're going to do some good. If you can't do that, you have no right in going ahead. I know one person who put together four different developmental screening tests. None of them have any data on their accuracy. What concerns me is what's going to happen as we make up more and more of these procedures and subject the public to them without even knowing their accuracy. I don't think that's ethical.

How many of you people would like to have somebody do a cancer screen on you, or a screen for a thyroid problem, without knowing if the procedure is accurate? In the medical profession and in some of the latest professions such as speech pathology there's a tendency to totally overlook this issue. I think you ought to ask yourselves what you are doing and how well are you helping the patients.

I bring this up because our approach doesn't totally jibe with what HCFA has put together. When you are asked to use a particular screening package, you ought to ask that a case be made for it. If a strong case can't be made, then maybe you ought to forget about it. A lot of people come to you. The fancier the package they try to sell, the more suspicious you ought to be.

When we started with the development of the "DDST" in 1967, we tried to teach the physicians how to screen. We gave up on them after a while and trained the nurses. Later we said nurses were too expensive and trained paraprofessionals, some of whom hadn't graduated from high school. We went out and screened whole housing projects. We had about an 86 percent acceptance rate, and found that even if they turned us down the first time, we could get in the door if we went back a second time. But we thought "that isn't going to work," and came out with a pre-screening developmental questionnaire, the "PDQ."

You should understand the philosophy behind a pre-screen. The purpose of a pre-screen is to use a quick, simple procedure to identify those individuals who need a more thorough screen, because the more thorough screen is more expensive. If you do a pre-screen, it should err on the side of over-referral. If not, you're going to miss some who never get to the second screen. If you notice, they've started doing pre-screens at the airports. When the alarm goes off, that doesn't mean you're a hijacker. It says: you're suspect, and we need to look you over more carefully. So they comb you up and down and find out where you've got the metal. That's more expensive, takes more manpower, doesn't it? If you're still suspect, they take you in the back room and do the diagnostic procedure, get you undressed to see whether you've really got a gun or not. The scoring criteria of the pre-screening questionnaire are set to err on the side of over-referrals, with the idea that you'd cut down your over-referrals when you do the developmental screening test, which takes more time. If the child is still suspect, then he gets the diagnostic procedure.

The question about racial discrimination comes up time and time again, and you ought to be aware of it. You need to ask yourself: does disease present itself equally, in a fair way, to all racial/ethnic groups in this country? I'd say no. We know that children from poverty families, in which minority groups are overrepresented, have a much higher frequency of hearing loss. Does that mean we're going to set our norms for hearing for poverty kids on the basis of how well they hear? No. We're going to base it on what we think they ought to hear. Similarly, in developmental screening, if you're trying to prevent something like school failure, you ought to ask yourself: is this screening test designed to do that?

Thus, we got in on the same track. We standardized the screening test, we walked around very smug, and said: we've got data on a thousand kids.

Incidentally, we've got another thousand Blacks, Chicanos and Anglos, and found there was practically no difference in development between those three racial groups. Where there were differences was in comparing the white poverty kids with the white middle class kids. The poverty kids were advanced in their development up until 18 months of age. I think the Kauai study showed that ten times as many children fail in school later due to a lousy home environment as due to biological factors, such as perinatal stress. Racial and local norms are useful, but not generally useful in screening because they have not been shown to be predictive. They're useful from a diagnostic standpoint in trying to explain why this kid is different from that one. If you're acquainted with Jane Mercer's study, she showed you you can escape being labeled retarded by going to a parochial school. Parochial schools don't have classes for retarded kids. There are other ways you can escape labeling, as by moving around from one school to another. It takes them two years to find you.

The important thing to consider is what you're trying to do with the screening test you're going to use. I suggest that you be very hard-nosed about it and start out with screening for just a few conditions you can diagnose with certainty. If you want to add more later, fine. Where I differ with the HCFA guidelines is with their advice to use a questionnaire first. The literature shows there's only one thing in developmental history parents remember: when the child started to walk. Mothers remember birth weights, but that's not a developmental milestone. For current developmental status, we have shown that if you ask questions about things they could have observed, parents are quite accurate.

The other point I would make is about stigmatization. Errors have occurred, even in the PKU program. Babies classed suspect under PKU screening were started on a diet. That's a no-no. I totally endorse Nancy Stone's view that children suspect on screening need to have a further evaluation, and you shouldn't label or stigmatize them. I would say also that you shouldn't be counseling parents on the basis of a screening result, because screening is only presumptive, especially if you're basing it totally on parental reports.

We've also come up with some data on decision analysis, showing that if you identify children with developmental problems early in life, even when you subtract the cost of early identification, you can save $10,000 per child. The reason is you increase their lifetime earnings by increasing their ability to work.

In terms of our training program, by the end of the year there will be about 1,500 people who have been trained. We've found in teaching a physician when to make a referral to a psychologist, the question should be raised: does the psychologist know what to do with the zero-to-six-age child? They don't. Bea Moore raised similar concerns when she did her EPSDT survey. We found the same problem when doing a 52-program Head

Start survey in this Region. A lot of kids are mislabeled because of inaccuracies in the diagnostic procedures. The reason that psychologists, speech pathologists, PTs and others don't know about the zero-to-six-age child is that prior to the EPSDT program those kids didn't surface until they were school age. Once again, the reason for that was because the physicians didn't identify those kids early.

Tomorrow we can show a videotape giving an overview of our different training programs. We've got about 63 lessons that are exportable. We can come to your State and train instructors, who, in turn, would train other people. In Colorado, we've put together an advisory board, composed of people from EPSDT, the State health department, DD, mental health, education, Head Start, and the Association of Retarded Citizens and the Regional DD councils. We plan together where we're going to do the training. We go into a community and train people across the board, regardless of their agency. Local funding is cheaper when you work across agencies. An advantage in the lack of money is that mutual concern may promote more collaboration.

MR. COLLINS: Over the next hour you will be entertained; you will laugh, cry, oooh, and aaah as you look at some of the most creative ways in which people across the country promote EPSDT.

We believe that it is hard to promote a program if only a few people are capable of receiving its benefits. It's a lot easier to promote a concept behind a program. After all the things we've heard today, we're going to be better off if we promote child health for all children instead of a few. That is, people can get the same service through specific programs for which they're eligible, based on the concept we promote for everybody.

Now you will see, hear, and feel the results of some experimental programs from various parts of the country. One started in Seattle, the next in California, and then a parallel program from New Jersey. Afterwards, we'll tantalize you with a number of written pieces, TV commercials, and a special activity called "survival television." We'll close with a film developed about six years ago that is still a classic. I ask you to do one thing. Don't go away. I also know that most of you have just finished lunch. It's going to be very warm in this room. The tendency is to fall asleep, but if you snooze, you lose. To keep you wide awake and in the room, we have some gifts to be awarded by a public drawing from the hat. The numbers are in the hat in the order in which you registered, and you must be present to win. If you are not here, a new number will be drawn, and the prize awarded. Keep your eye on the gifts and your attention on the center ring!

(Slide presentation)

That was an example of the most recent health promotion campaign. I stress the health promotion part of it because it is not specifically on EPSDT. We felt that if we could advertise health and the concept behind health screening we'd get a lot farther than if we went after strict EPSDT promotion. As was indicated by the slide show, this campaign was picked up by the State of California through the assistance of Region IX Health Care Financing Administration.

Next on our program, a representative from California will describe how "Check It Out" was adapted there. She is the Director of Health Education for the Orange County Human Service Agencies in Santa Ana, and also the director, producer, and moderator of her own television series about health and the health of children. I introduce to you Claire Mueller.

MS. MUELLER: I'm going to let you see what we did in California about "Check Out With a Check-Up," from the sign that said "Do It!," and we did it in California, in Orange County in particular. First, listen to this song Bill's going to play. Listen to the words.

(Song played.)

Let me tell you a little bit about that song. It was an original song done by Alameda County. In Orange County we adapted it for the "Check It Out With A Check-Up" campaign and developed seven choreographed songs and dances. When the campaign came along we had the great idea to storm Orange County with it. My marketing strategy is to start at the top and blanket an area like Madison Avenue does, with messages in every newspaper and special activities. You talk to all the politicians and every conceivable layer in government and all the community organizations and so on.

I started with the Board of Supervisors, to let them know first. We played the song you just heard in their chambers, and gave a little speech on what this campaign was about, what was going on, what it meant and its objectives. Then we brought in the dancing children in their red tights.

(Slide presentation.)

This was the first time in history something like this had ever been done, and they sat there with their eyes open. The Board of Supervisors meetings are very stuffy, and here these little kids come running in in their red tights, singing "Check-ups," and the Board of Supervisors absolutely loved it. They were standing up, clapping their hands, shouting, it was like a hoedown.

This afforded an excellent opportunity, since not only were the Board of Supervisors there at their meeting, but all the political people and the media. The press room is right across the hall, and all the press people were there. At one fell swoop we let everyone in the entire county know what this campaign meant and what was going on. The next day it was on television and in all the papers. With one smashing kind of activity we got the word about the campaign out, that it was going on, and everybody knew about it immediately. That's how we started.

(Slide presentation continued.)

Then we took our famous dancing troup out into the community to meet the people. We went out to all the malls. A hundred thousand people go through these malls on a weekend. We did them on a Saturday, and I had my staff members there. It's not enough to entertain people, we also have to talk to them and give them some health education, tell them why we're doing this, why it's important to have a checkup. So I had staff people there at all times, talking to people after each presentation.

We're trying to reach the adolescents, the 10 to 14 year olds. Where do you think they are in California on a hot summer day?

CHORUS: At the beach!

(Slide presentation continued.)

MS. MUELLER: You've got it. So we did a special promotion, and it was a smash success. We put 450 bus posters on all the buses in Orange County. We got Safeway to print "Check It Out With A Check-Up" logos on grocery bags. Messages were printed on all the AFDC messages, we mailed slips to all the providers, we blanketed the county. As I mentioned in the beginning, my feeling about marketing is that you have to hit everyone. We had it in all languages, in the Indochinese newspapers, and in Spanish and English, and developed special promotional campaigns. Everyone loved it, it was a huge success. People still come to the office and want "Check It Out With A Check-Up" buttons.

Remember the International Year of the Child? We decided we'd do something special in Orange County - have a health fair. Now, a health fair doesn't sound like the most exciting thing in the world, but we wanted to make it exciting, so we used the same kind of marketing strategies. The first thing we did was to rush down to the Board of Supervisors and tell them we were going to put on the tremendous health fair, and that we wanted a proclamation. They printed one up for us, and August 28, 1979, was Child Health Day in Orange County. I want to show you some slides of what we did.

(Slide presentation)

The point of these slides is to let you know how, if you want to promote something, to get something done in your county, even with tight budgets. We all have budget problems, but you can always go to the private sector, which I have found to be very cooperative. I tapped Home Savings and Loans, for example. Every county in your State has someplace that would probably give you money, given a chance.

(Slide presentation continued.)

The point of this shot is to let you know that, when you have an event, have something unique, a different angle, interesting activities and entertainment, and the people will come. They are there to get something out of it. They love it, and they're interested. I invited all the politicians over, I wanted them to be involved, too. You have to have a broad approach, involve all levels of the community. You have to hit all the media, because the media wants new and interesting things in their papers and newscasts. And you have to be enthusiastic yourself - you really have to get out there and sell health. If you are, and do, they'll come. That's my message to you today.

Let me show you some other things. These are iron-on T-shirt transfers. My staff ironed these on their T-shirts and wore them when they were down at the beach and being very "in the mood." Here's one of the posters which were all over the county, and these are the buttons. Those are

handouts and things we gave out free during that campaign. Public health needs to have a little jazz, a little spark, to make it fun. I want these kids to come back and really like the health department, I want them to come in here and have a good time, so I called up Carl's Jr. and told them about our health program. Carl's Jr. is like MacDonald's - hamburgers and fast foods. Every child in California knows about Carl's. I wanted them to give our children a coupon for a free hamburger they can take home when they come in for their checkup. Carl's Jr. gave me 10,000 free coupons. We handed them out, and pretty soon the kids wanted to come back to the health department. It was a way to get them interested in health, educate them subliminally. The experience of coming became a fun experience and they got a pleasant feeling out of it. Another thing we did was give the kids large gold stars when they came in to get a shot. We also did these coloring books in Spanish and English called "Your Health Checkup Trip." They colored while they were waiting, and we gave it to them to take home for their mothers to read to them, so it was also an educational tool.

We also had an interesting approach to training. We developed an EPSDT crossword puzzle instead of the same old question-and-answer evaluation. Another successful method in promoting health was to put our message on electric signs. Many counties or many States probably have electric signs. I saw a bank's electric sign, and I went in and said: "Can I use your sign for our CHDP checkup project?" They agreed to let us use it, so about every five seconds this message blinked in the middle of a big intersection. You can utilize unique kinds of things in your community. You can go out and get to know the people, develop rapport, and use all these things at little or no cost to the county, and do a lot of promoting and marketing that way.

AUDIENCE QUESTION: How many people actually got services? Could you measure the results?

MS. MUELLER: We measured to see if the adolescents were coming in. Their rate went 'way up for about two months, while the campaign was going on, and then leveled off.

AUDIENCE QUESTION: What was your total budget?

MS. MUELLER: Would you believe, zero? There's no extra money in my budget. The CHDP budget for promotion and health education was $5,000. All of this was done at no cost, and that's an important point. The dancing was done at no cost, all the costuming was done free as a public service to the community. Mickey and Minnie Mouse were free. If you approach people to do it as a public service, for the health of children, they'll get a lot of good PR out of it. The dancing school did the PR. If you approach it a certain way people can be cooperative.

AUDIENCE QUESTION: I was wondering about your providers.

MS. MUELLER: In the beginning we sent out notices to the providers. Our private providers now screen 56 percent of our CHDP children. It used to be much lower. We have approximately 88 active private providers, I mean the ones that really do it, not the ones that sign up and never do anything. I work constantly on the private provider program, and Siegried Centerwall visits the doctors if they're slacking off, going to their offices and talking to them and updating them, trying to motivate them to continue working on the program and asking them what problems they encounter.

MR. SMITH: I appreciate the approach of focusing on child health without narrowing in on EPSDT. Was there any measurable result on the EPSDT program?

MS. MUELLER: In California we call it CHDP, but it's EPSDT. We have a staff of people who take EPSDT referrals. There was a measurable difference as far as screenings go. That's one of the reasons I feel it was a success.

AUDIENCE QUESTION: We find that people are not literate in Spanish and English. They can't read Spanish, but they speak it.

MS. MUELLER: We have both problems in Orange County. We have bilingual staff who work with Spanish-speaking people to help them understand. If they're not literate in Spanish, that's another problem. We try to encourage the people that are relatively literate in Spanish. If that doesn't work, we interpret for them.

AUDIENCE QUESTION: Do you have funds for publications?

MS. MUELLER: We have funds for this coloring book, and our brochures in Spanish. We also have everything in Indochinese now, Laotian. We have to have all the various dialects because of the high Indochinese population in Orange County.

AUDIENCE QUESTION: In the northeast, where I'm from, most of the communities are uniformly poor. It sounds like some of the resources you used were coming from an upper class population. I'm wondering how to bring the concept to another county or State?

MS. MUELLER: Well, I think Mickey and Minnie Mouse are unique, because Disneyland is in Orange County, but my focus is on intermingling the private and public sectors. I think that's one of the things we public health people don't do enough - go out and tap the resources of the private community. They have money and all kinds of things which could help us. Every person in this room can go out and ask for things and create unique situations.

In Orange County there are all socioeconomic levels, from extremely wealthy to ghetto areas where a couple of families live in one room.

Mixing needs to be done. It gives the lower income people an opportunity to do things they normally wouldn't be able to do, and it gives other people a chance to do something to help the community.

MR. COLLINS: Each of the presentations is presented not so much to be imitated as to spark your imaginations. I'm convinced that everything can be topped or improved upon. If you see something here you would like to try, but can do better in your own place, I'd like you to do it and then tell me about it.

The next part of the program deals with, you'll pardon the expression, a couple of clowns I met in New Jersey Medicaid. I'll let the Bureau Chief of the Child Health Services Branch, New Jersey Medicaid, introduce the next act. Dr. Ruth Stekert.

DR. STEKERT: Claire, $5,000 sounds like a mint to me. We've had the same budget crunch every other place has had. Two or three years ago, in addition to the coloring books and poster contests, we wanted to conduct a drive for recipient education in child health. We wanted to promote positive attitudes about health, and we wanted it geared to the general health population, not just the EPSDT population. The question was, how to do that without money? Well, we scrounged around, and two of our five field coordinators, who are always being urged to put on demonstration projects, came up with the concept of having a clown show. As a pediatrician, I felt we ought to gear this to the pre-school population; teach preschoolers fun about health and teach them general health. How would we measure whether or not we were successful? We would perform in areas where there were large groups of children: in summer camp programs, Head Start, day care, public schools, fairs, that sort of thing. We would develop a test to test the retention of both the instructors and the children.

We would also present this to children before they went for their physical examinations in school. We would divide the population up in three groups; one of whom would see the clown show, one that would just mingle with the clowns, and another that would not see the show or have any contact with the clowns. Then we would judge their acceptance, their reaction to the health program in school. It goes without saying that those involved in the clown show were more positive. We had less crying and more acceptance. In the course of that one year we reached between four and five thousand children. This was a heterogenous group; Medicaid and non-Medicaid.

This was always a live presentation. When I attempted to bring the clowns here we couldn't do it, we didn't have the money. So, in the course of about 48 hours we developed a group of slides for presentation. I cannot tell you whether or not this captures the ethos of the live presentation; I hope it has lost nothing in the transition. Remember, this is a presentation for children, preschoolers, it was never meant for an

adult population. So, I'm going to ask you to cooperate, close your eyes, and regress in time to young adulthood, down to childhood, to the preschool stage, and come and enjoy. Incidentally, it's called "Check Out a Check-up."

(Slide presentation)

Are there any questions? One is a nurse and one is a schoolteacher. They had a professional clown teach them. Our total budget to develop initially, without these slides, was $200, and the Department of Public Welfare helped to set up the slides as an emergency measure.

AUDIENCE QUESTION: Your clowns were volunteers?

DR. STEKERT: They're members of my staff, and they did this in addition to their regular work. We have five service coordinators, three of whom are nurses, one is a schoolteacher, and one is a social worker.

AUDIENCE QUESTION: How did you translate the clown show into getting the children in for a checkup?

DR. STEKERT: It's just amazing. They go home with coloring papers, sometimes we have a poster contest. If it's in school, then the teachers talk to them, and afterwards, maybe in about a week, we give them an examination to see how much they've retained. Now, you would have to see this in operation to appreciate the fervor and the glee and the giggles. You come down the hall of the school to the auditorium where the clown show is being held and you hear happiness.

MR. HISCOCK, CHAIRMAN: As George Silver pointed out in his keynote, we're at a point in time when health programs must cooperate or perish. This calls for hard work to search for a common interest among heretofore disparate interests, and with that interest, build a working coalition.

Our frame of reference is the recognition that first, there are many child health-related programs; second, that our human and dollar resources have limits; and third, and most important, that health needs of poor children persist. Our mutual quest, then, is to develop effective working relationships so that the needs of our various child beneficiaries can be effectively, efficiently, and economically joined with the State and Federal health resources we are called on to manage.

Our panel is well qualified to discuss this quest. They come from a variety of disciplines and operating bases. As they bring their messages, I hope you will be conscious of common themes and perspectives; and find some ideas for strategies you can apply back home.

We should focus our attention on two vehicles: planning and strategies. We have been discussing a child health action planning vehicle with the TAG. You have a draft discussion outline of such an approach. Our concept is to replace present intergovernmental procedures with an accountable, performance-oriented planning process. State Medicaid agencies, in consultation and negotiation with HCFA Regional Offices, would set forth specific feasible objectives and action steps. These would serve as the basis for State and Regional program assessment and decisions. We have already alluded to the other focus, a Departmental child health strategy to maximize Medicaid's health care financing mechanisms with preventive service mechanisms of other child health resources such as Maternal and Child Health and Crippled Children's Services under Title V, Head Start, schools and community health centers.

Our first panelist has had such interesting experiences and accomplishments, which she shared last year at the American Public Health Association, I asked her to bear a hand here today. Joy Morell, the Director of Field Operations for the Vermont Department of Health.

MS. MORELL: In the late Sixties, Vermont had very rapid growth and bought into a number of Federal funds. Our growth was about 690 percent. We had a lot of activity implementing, but we didn't spend much time in planning. In 1977-78, when those funds began to look like they were tightening up, for not only public health programs and EPSDT, and we were having to be more accountable, we began to think about how to maximize our services.

I work for the Vermont State Department of Health, which is part of the Agency of Human Services, as is the Department of Social Welfare. While we're all brothers and sisters in some ways,

we all fight like cats and dogs for a piece of the pie. What we forgot along the way was the one most important individual: the client, the person who was having to come to the Health Department or to the Welfare Office a number of times to receive the same service.

Our job was to maximize services to clients and to minimize our costs. In 1978, we completely reorganized our Medical Services Division and field offices, and made generalists out of everybody instead of specialists. Change for any individual is very difficult. Most people cannot cope with change when it affects their individual program and the people to whom they deliver services. I can't begin to tell you the toil and sweat we went through in integrating the Maternal and Child effort, Title V and Title XIX's EPSDT, but I can share with you that I believe it's been successful. An individual who presents himself to the Vermont State Health Department, whether Well Child, MIC, C and Y or EPSDT, can expect services.

In terms of the planning process, I participate in planning with WIC, EPSDT, and Title V, which is the handicapped children's services, Crippled Children. Vermont is a small-enough State so that we can know the people who provide programs and services to all the minors. That concept may not be applicable in other areas. The other Vermont characteristic is that we don't have county health departments. Our district offices are State offices. So we share unique opportunities to be able to develop an integration of health services for all programs. Other States with many political boundaries and local control often can't do that.

MR. HISCOCK: Thanks, Joy. We'll hold any comments, questions, until the end. I'd rather get the whole kaleidescope before us. Next, Dr. Bob McCurdy, who, as a State MCH/CC Director, will share with us his perceptions of opportunities for collaboration and how mutual efforts can be achieved.

DR. McCURDY: In Colorado, it's a little bit different from what Joy described for Vermont, in that the Health Department and the Department of Social Services are separate agencies. Also, in Colorado we have local, autonomous county or district health departments. They're not branches of the State health department. Some of the things that I think the health departments, specifically the Title V, Maternal and Child Health, and Crippled Children's programs can give EPSDT are not only outreach to families in the local areas and case management assistance (which Dorothy Clarke, the able Director of this program in the Health Department, will describe to you later on), but quality assurance and standard-setting. For a long time State and local MCH and CCS staff have been assuring quality, setting standards for care, and reaching out to various providers in the community. They are familiar with it, and have developed skills in outreach and follow-up with families.

The local public health nurse or community health worker may be looked upon more as a health-related, helping, assisting person than the local or county social services department case worker. In Colorado, there was a problem with the EPSDT program reaching the children, and also ascertaining whether or not they got from the screening to diagnosis to treatment. This is where the Maternal and Child Health Division of the health departments were able to work well with the EPSDT program, which is in the Social Services Department. Being in separate departments, different parts of town, these little things are important, and make communication and working together more difficult. I believe you should find similar potential for increased quality assurance and standard-setting in your States.

MR. HISCOCK: Bob is also the Chairman of the Colorado Chapter of the Academy of Pediatrics. Do you want to talk a bit about private sector involvement from your perspective as the Chapter chairman?

DR. MCCURDY: When they see or learn about a public health program or a social service program, some of the pediatricians, and family practitioners, too, tend to see a red flag. That's being honest. Not all of them feel that way. We've been very careful in Colorado to make sure that freedom of choice is carried out, and not to exclude the private practicing physicians in any way. I believe I'm correct that over half of the screenings in Colorado are done by private practitioners. They are very much involved, and have some of the same programmatic complaints as we administrators. They complain about duplications of screenings, about the patient who goes to a health department or a physician and gets screening, goes to another, and gets screening again. It's a legitimate complaint, because it is hard to sort that out and keep track. We hope that the MMIS is going to help with that. They also complain about reimbursement. That's a very complex, but legitimate complaint, and one that we've worked on. I think it is under reasonably good control in Colorado, except for some glaring examples of terribly low reimbursement for physician's services.

There's been good cooperation because of bending over backward to ascertain that there is freedom of choice, including the private practitioners in the EPSDT advisory committee, and getting their input. Everybody complains about forms and paperwork, and the physicians are with us in that. Despite the fact that the Colorado Chapter of the Academy of Pediatrics was involved in developing the form there are still complaints. You're never going to satisfy everybody's problems or complaints, but because of the good collaboration and everybody respecting everybody else's turn, trying to understand the other person's point of view, I think it has worked out well.

MR. HISCOCK: Next, we'll hear from Susan Hunt from North Carolina. She knows how difficult it is to achieve a common interest among 54 or so different packages.

MS. HUNT: North Carolina has similar problems to Vermont in coordination. One thing that really helped us is that about three years ago the legislature recommended that EPSDT and Medicaid be taken out of the Department of Social Services, and that has been invaluable to us. We are a separate agency in an umbrella agency. We have a Division of Health Services which we call our health department, a Division of Social Services, and then a Division of Medical Systems. As State EPSDT Coordinator, I find it easier to coordinate with the local county departments of social services and the local health departments because I'm "outside." We're "outside" to 100 health departments and 100 county offices of social services. They're all like individual States who want to do their own thing. Even though we coordinate closely with the Academy of Pediatrics and the Division of Health Services and the Division of Social Services to coordinate, we have to get that coordination down to the local level. Most of our problems arise in trying to provide "X" amount of services to all eligibles without duplication. In North Carolina, EPSDT is caught between Title XIX and Title XX. In the local county departments of social services the eligibility workers explain program twice a year: at eligibility intake, and again at redetermination. Recipients requesting support services are referred to the services intake, which is Title XX.

That's a problem because of the penalty regulation. We have more documentation requirements, and we don't have the people to do the documentation. In our budget, we requested transportation and EPSDT outreach coordinators so that we could assist the counties wanting the special services. Because of the Federal budget cut, it wasn't appropriate to request Statewide social workers when our Division is having to cut medical services. We'll have our optional services to pay for.

Another problem we've found in the counties is that we have so many different child service agencies that coordination is difficult. Children are eligible for EPSDT at times and then may lose eligibility. It's good that the child doesn't lose his services with our Maternal and Child Health program. When the child is Medicaid-eligible, the departments bill Medicaid.

MR. HISCOCK: How is California proceeding with planning and legislation to bring multiple-agency, local child-serving programs together?

DR. CENTERWALL: Bill referred particularly to the Child Health Initiative task force which was set up in California by the Director of the Department of Health Services, Beverlee Myers. The reason for that task force was related to the fact that the counties, as in Colorado, are very independent, but are also trying to put together a coherent program: one that is meaningful and relates to families who sometimes are eligible for several different services. These programs have various planning and recording requirements, different eligibility criteria, and have developed their own individual systems which come down from the Federal level to the State level, often through different departments, and

through the State level to the local level. Actually, they are trying to deal with very similar families or through the same health services, such as a child health clinic.

As Beverlee Myers began to read the decreased funding writing on the wall, she thought about going and asking for block grants. That way, she might be able to give money to local people with less paperwork and fewer strings attached, so that the programs could serve as many or more children, with less overhead and less administrative costs. She felt that one of the best things to do would be to set up an all-California task force to interpret to the State what the local level needed to make child health programs work. She asked them to relate particularly to the ones that came throught the Health Department, recognizing that there are mental health services, Developmental Disability services, and school services which are focused through other departments over which she had no control, but she recognized that's also part of the problem.

She appointed 32 people from all parts of California and from the public and private, non-profit sector. Some were from voluntary agencies, community clinics, a health officer, former health officers, a nurse from the local health department and a CHDP director. When it began it looked almost hopeless. They were from all over, from rural and urban areas, and saw different problems from different perspectives. What seemed like an answer to one person seemed like a problem to another. They spent a couple of meetings just brainstorming and multiplying each other's problems, presenting a problem for every solution. Finally, they decided to come to grips with the issues, and they set up a three-day marathon meeting in which, every day, they would write some version of a plan for the State. They wrote their drafts at night, came back and tore them apart the next day, and rewrote them the next night. They came up with a credible document. If you are interested, write me for a copy of the report.

They were interested in simplifying access, in seeing that, as in Vermont, a family could go through one door to access resources in a simple way at one site. They were always reaching out beyond services that were available from the Department of Health Services. You can't focus on just health services. They were also interested in getting the Department of Health Services to simplify and unify elgibility. They'd like to have a baby that starts out on Medi-Cal (Medicaid) be eligible through the whole first year of life at least, and not be dropping out. At the outset, they wanted State level coordination and integration of the Maternal and Child Health (Title V), immunization, CHDP, and WIC programs. They said you shouldn't have to make separate and distinct WIC, CHDP, Maternal and Child Health, and immunization plans, as is done now, in order to get those monies filtered down. The reason for the Maternal and Child Health plan is because the State feels its plan should be a compilation of the county plans, where they actually deliver the

services. The task force also wanted to have our State Child Health Board (now advisory for CHDP only), advise the Director about child health as a whole. The Board would look at the question of coordinating and integrating these four programs and then coordinating with other programs and outside agencies. The legislation Bill mentioned was to amend the State CHDP legislation and rename the Child Health Board the "State Child Health Council," so that people would know it related to all maternal and child health. We would also have local advisory boards in each county. We haven't asked HCFA what this will mean in terms of funding because we're funding them right now.

We've always felt that our local CHDP Advisory Boards should look at the total resources, the total picture of child health services, just like promoting child health. We look at the availability and program we expect in the counties. If available to all children, it's available to CHDP children as well. So that's where we are. We're just starting to try to carry out the report's recommendations.

MR. HISCOCK: Thanks for that interesting commentary. Now, let's move to Education with Lynn King from the Regional Office in Kansas City, Missouri.

MS. KING: If there is anything more difficult than coordination or collaborative efforts at the State and local levels, it's a collaborative effort at the Federal level. Fortunately, in Region VII we have four States; Iowa, Kansas, Missouri, and Nebraska, and we work with HCFA and the Public Health Service and have a terrific team approach. Everyone is cooperative and considerate, and it's just been fantastic.

A couple of years ago, the then Office of Education was reorganized, and I was assigned EPSDT. After finding out what it was all about and its impact upon children, I have been overwhelmed with statistics and facts and data on EPSDT and Medicaid-eligible children in our Region.

The first step we took after the Office of Education and HCFA signed the interagency agreement was to coordinate meetings with our State departments, divisions of family services or social services, and the large urban school districts in our Region. We called ten large districts to the State meetings, along with the State department and the local people, to get a dialogue going amongst them. Then there were subsequent State and local meetings between districts and local Medicaid people. We were very much behind the EPSDT effort, but there was no way we could force the school districts to include Medicaid screening into their currently existing health programs. School districts didn't have the budgets to do that, and some districts felt that child health, while very important, was a service detached from education. We hope we have changed that attitude in most of our districts.

We had some success stories by February 1980. A small school district in Independence, Missouri, signed an agreement to include EPSDT services in their school. They are now operating with Head Start children. Currently they hold screening at only one site. The Kansas City, Missouri, school district has signed an agreement with State Medicaid and included EPSDT screening in their school health program.

The Des Moines, Iowa, public school system has signed a little different agreement. When Public Health Service became the third prong of this effort we started talking to school districts about being not only providers of services, but outreach centers. By outreach centers we meant that they would refer children who had, or were suspected of having, medical problems to one of the local providers.

The Wellston School District, a small district in the St. Louis area, has signed an agreement with the local health department to provide screening. About 90 percent of their children were Medicaid-eligible, but there was really no health program in the school district. With the help of the neighborhood health centers and the Public Health Service we managed to get a collaborative ageement going. I guess our biggest success story was in the St. Louis, Missouri, school district, which recently signed an agreement to incorporate EPSDT screening through the local and neighborhood health centers into its health program. St. Louis has approximately 60,000 students, about 50 percent of whom are Medicaid-eligible, and who may or may not have been receiving services. It may seem a small effort, but it's the first step, and without the first step there can be nothing further.

We're proud of our Region's efforts, and the collaborative efforts of the school districts, the Department of Education, HCFA and the Public Health Service.

MR. HISCOCK: Thank you, Lynn. Would you pass the microphone to Dorothy Clarke? Dorothy is the Manager for Outreach in the Colorado Health Department, doing EPSDT work for the Department of Social Services.

MS. CLARKE: I need to mention that I also direct the Robert Wood Johnson School Health Project. While I will talk to you about the collaborative efforts between Social Services and local agencies, respectively, I'd also like to share some relationships with a school district as provider of EPSDT services.

I thought I knew everything there was to know about presenting an issue clearly and getting some resolution. Once I went to Pueblo, Colorado, and presented my spiel on the EPSDT program, recognizing first of all never to use an acronym, so that each time I said it I had to say "the Early and Periodic Screening, Diagnosis, and Treatment program." After I had taken about 20 minutes to present it, the County Commissioner told me "We'll get back in touch with you." Ten days later I met a man at a

meeting who told me that they had told him that someone had been in Pueblo "talking about some kind of health program, and we didn't know what the Hell she was talking about." Well, I asked him if he would help me. I made another appointment to present my spiel, and he went with me. I said "The Early and Periodic Screening, Diagnosis, and Treatment Program is designed to ...," and then he'd interpret it. He got the contract.

Local autonomy is significant in Colorado. I have heard everything from "We don't like State government" first of all, and "you people in government think you have all the answers," to "I'm so sick of the Federal government I don't know what to do," to "I don't know if I like socialized medicine," to "I pay a Hell of a lot of taxes," and "What about those people who are just above the poverty level?" and on and on. I say to them seriously (and this is part of our training philosophy) that the focus is always on the child. While there are not enough data available to prove that preventive health is less costly in the long run, in fact, that is true. I talk in terms of my being an educator and a parent, and I know that children learn better when they feel well.

We contracted with the State Department of Social Services in December 77, then subcontracted with a diversity of county health nursing services, organized health departments, and Head Start programs. We have 13 subcontracts with the local health departments, 30 with the county health nursing services, three with local social services, three State-based because I just couldn't convince county commissioners they ought to have this kind of program in their county, and three with local Head Start programs. We feel it works well because, again, our investment is with children. We don't deal with turf at the State Department of Health, or with the county programs. We don't really care who gets the credit. We want to make sure that we can assure the State Department of Social Services that we're doing what they have contracted with us to be done.

I've mentioned our child-focused philosophy, but there's also a philosophy related to public health nursing. Our training program is modeled after public health nursing and social work concepts. We try to assure that outreach workers are not tainted by a negative image of local social services. We try to keep outreach workers free of the complaints from medical providers about reimbursement or its slowness. We see our outreach workers as advocates, not only for EPSDT, but for preventive health services.

Three years later, we're now negotiating a contract renewal with the State Department of Social Services. To capsulize, I'd say modestly that the outreach workers have been able to establish trust with other human service agencies, although we could not have established that trust if the social services and other agencies had not been receptive. We keep hearing that turf is an issue, and it is an issue until we start talking about it. We say we really don't care if you get the credit, as long as

the child gets into the program. I guess that's our philosophy and the State Department of Social Services' and the State Department of Health's.

MR. HISCOCK: Thank you. We'll move along to another school perspective with Wes Parnell of the Merrimac Center.

MR. PARNELL: I was interested in Dorothy's comment about the local autonomy of Colorado, because it gave me some insight as to where the migrating New Englanders are going. I'd like Dorothy to come to Massachusetts and face 351 town meetings and see local autonomy at work.

I come from an educational service center that works with 22 towns and cities in northeast Massachusetts. We're a not-for-profit organization, and we do just about anything local school systems would like to do in collaboration. Several years ago, in working with other human services agencies, we joined a Regional task force looking at ways we could collaborate across agencies: mental health, an office for children in the Division of Youth Services, welfare, as well as education. Out of that came an interest in taking a look at some of the mandates that are similar across agencies, specifically Medicaid's EPSDT. We looked at a school through the mandatory health examinations, either by the school or through private physicians, of children at certain age levels throughout their school career. In Massachusetts, it's usually at Kindergarten, Grade 4, and Grade 10. In addition, under the special education mandates, anyone referred to that program needed to have a home visit and medical coverage as well as an in-depth psychological assessment. Those three agencies alone provided some similarity for what needed to be done.

Through a HCFA Research and Demonstrations grant, and cooperating with the Department of Public Welfare and the State Department of Education, we began an EPSDT program in a large public school. Working closely with the private providers, we had agreements to accept referrals from our projects. We referred them on the basis of concerns identified through the developmental and direct health assessments done by nurse practitioners and, a couple of days a week, a pediatrician's consulting services. The providers in the area accept our referrals and provide us with feedback on whether or not our screening decisions were correct, and what's happening with our youngsters. We're also able to work closely with the families to make them more aware of what services are available in the community and to what services they have the right to access. We work with all youngsters in the schools, regardless of whether they're Medicaid-eligible or not, and we have been successful in enrolling 87 percent in the participating schools.

We are now at a point of integrating the health program of the Lawrence Public Schools with our own project, which means that the nursing staff of the Lawrence Public Schools will now become a part of our staff. We are integrating immunization, vision, and hearing, along with the EPSDT protocols we're implementing, and we're going to be able to follow through

with youngsters and families in a much more comprehensive and, we think, effective way.

MR. HISCOCK: In the back of the workbook is a description of HCFA's child health strategy which was mentioned before. Our Office and the Office of Maternal and Child Health in the Public Health Service take that strategy seriously, and try to facilitate achieving it in the Regions and across the country. John Shwab is one of the people with whom we work, and wants to say a couple of words on his perspective of that strategy.

MR. SHWAB: I think it's important for State managers to know how we are getting together, working in a full, open, and constructive way. The job is made easier because we have a healthy respect for one another. If you're deliberating with your other agencies, we are there to support you in trying to make the job a little bit easier.

I want to share our conceptual framework for the child health strategy from the viewpoint of the Office of Maternal and Child Health. It's also important for State governments to know that, regardless of what form a block grant or consolidation of programs takes, you are going to have to get involved with agencies, particularly the State health agency, in a different way than you have before. The outside constituency, for the most part, is recommending that the blocking at the State level essentially include maternal and child health, crippled children, sudden infant death, genetics, family planning, adolescent pregnancy, and hemophilia.

At the core of the child health strategy is a concern for the total family, that the child can only be healthy if the total family is healthy. Then around that are several different aspects of making the family healthy and/or implementing the child health strategy. A major part of making the family healthy is prenatal care. Child health stragegy is concerned about perinatal care, not just ensuring that the pregnant woman is healthy and strong and not at risk for having a baby who may have some developmental or physical problem. It's following up the child through the first year of life, trying to reduce the incidence of handicapping conditions in child development. Another major concern is for the adolescent, and not just adolescent pregnancy. Over 51 percent of all births in the District of Columbia last year were to teenagers under the age of 16, 75 percent of them not married, and they're a high risk group. It's not only a concern for the adolescents' physical health, but to help the adolescents know more about growth and development and be better prepared for parenthood.

Finally, we have a concern for family planning, not just as population control, but to help men and women know about spacing children and be concerned with making the family, and therefore the child, healthy.

MR. HISCOCK: I want to wind up with sharing a nitty-gritty child health strategy that guides our lives. The Public Health Service and HCFA have

identical targets for managers' job expectations, on which performance ratings are based, including raises or transfers. This is a way to translate child health strategy expectations into action for interagency collaboration. Specifically, Central and Regional Office managers should be looking at Title V and Title XIX interagency agreements and their effectiveness, not as pieces of paper, which is easy to do, particularly if you have an English major or a lawyer around, but at what does the agreement really produce? Why are we doing it? Those kinds of questions.

Secondly, the strategy recognizes that community health centers, Title V projects, the programs or projects providing personal services, should be effective providers of EPSDT services. People may not like numbers games, but again, we ask: are they indeed becoming providers, and should they be? Are they being reimbursed, and are they billing? Is there a hangup on the Medicaid side, the health department's side, or the existing local community's side? What can we do to overcome the barrier? That's just another way of translating the strategy of collaboration into administrative action.

We've run through quite a kaleidoscope, and I see we've run out of time. I want to thank the panel for their different perspectives and for their candor. That's what this working conference is all about.

MR. HISCOCK: As some of you know, last December HCFA decided to shift its approach to monitoring EPSDT program performance. After much study and discussion, in which the TAG and the Office of Child Health were deeply involved, HCFA decided to move from the quality control approach to a State performance assessment mode.

To provide you with a brief orientation and status report, we added this session to today's agenda. Development and coordination of State assessment is the responsibility of the Office of Standards and Performance Evaluation in the Bureau of Program Operations. I am pleased to introduce Kenneth Koppenhoefer, Deputy Director of that Office.

MR. KOPPENHOEFER: We had minimal involvement with the program up until a couple of months ago, when there was a shift in responsibilities. Let me briefly describe our Office of Standards and Performance Evaluation. Primarily, we're concerned about the development of standards. So far we have developed standards for the contractors in the Medicare program and the package of standards for the MMIS recertification. We're also responsible for the overall State assessment package that has been used for two years in assessing the Title XIX, Medicaid, program. We're responsible for the MMDS reporting mechanism. Finally, we're responsible for reporting and recovering overpayments and reconsiderations. For those of you who may not work with or be aware of it, our State assessment package covers all the core areas of Medicaid from administrative management to reimbursement to utilization controls.

Until two months ago we did not have a real relationship with the EPSDT program because HCFA was trying to determine and assess EPSDT performance through a scientific sampling of cases at varying levels. Then the HCFA Administrator was advised that about 100 man-years were needed to carry that plan out. Having concluded he had no more man-years to give, he deep-sixed that project and asked if we would take it on as a part of the State assessment program, with the proviso that it would be operational by October 1, 1981.

How can these people get it operating by October 1? Quite simply, we're motivated by money. Once it's put into our work plans, it's a contract we have with HCFA. If we get it going by October 1 and it's a decent product, it means more money. If we don't, it means less money. We will have a package the Regions can use by October 1. In fact, we expect to have it out in September for pilot testing..

Before I tell you how I envision our program working, what it will look like, and how it will be utilized, let me tell you what it won't do. It will not be an assessment of the penalty regulation. We made it quite clear to the Administrator that we would take on this assignment, but our

Office wanted nothing to do with penalty regulations or penalty assessment. I find that type of thing repugnant. I don't think you need a club to get people to do something. When you're trying to assess and improve performance, you've got to have a partnership situation. I admit that HCFA has a problem as long as those regulations remain. I hope that those people who sit on the sunset review panel and judge the regulations will give them a quick and merciful death.

How do a group of people with only a couple of months of experience have the audacity to develop a set of performance requirements that can be used by the Regional Offices? The way we do it with the rest of our program is to work through our Regional Offices. There are highly trained, talented, motivated groups of people in our Regions. We call them together in a work group setting and give them a bare bones working draft to start from. They put the meat on the bones and, lo and behold, out comes a good finished product.

We started work on that product this week. Since Monday, we have been working with five Regional Office people and Bill Hiscock. We'll have the package ready by the end of the week. It will be rough, but we'll go back and polish it, and plan to send it out to the EPSDT TAG and, through it, to the States, for review and comment sometime in April. When the comments come back we'll polish it a little more, and intend to have the entire package out to the Regions as a finished product in early September. That will give the Regions enough time to do pilot test it, if they desire. We also want to get it out early so that State program managers can look at it and do a self-assessment before the Feds come marching in. The package will have not only the requirements, but the methods of evaluating acceptable performance levels. Thus, you will know very quickly what you must do to pass the requirements.

EPSDT is a bit different from our other core areas, which are functional. EPSDT is a program in and of itself. However, I think the methodology we've used for the regular program will work very well. We try to put the essence of the entire EPSDT program in a short paragraph or a long sentence. Then we have what are called criteria, and we've broken the EPSDT program and requirements into eight or ten major groupings. Under each criterion we have an element, or set of elements. We have weighting scores for each element and criterion. For example, there might be a couple of elements in the periodicity criterion. A reviewer would look at those elements, assess whether or not the State has performed adequately, make a notation, and determine whether or not the criterion has been met.

One more thing regarding the penalty provisions. As long as they're on the books, I don't think HCFA can ignore them. As far as we're concerned, if you pass the provisions of the State assessment process, then there should be no review for penalty purposes. However, as long as they remain on the books, if someone reviews the operation and finds a bad situation, that would be reported.

I would call the assessment package a combination of process and performance. We've tried to make a happy marriage the first time around, to look at those processes we feel necessary, but to also look at the outcome, the performance. The package will be good this year, I think. If past history is any indication, it will be better next year, and even better the year after that. We intend to improve this package every year, and our ultimate goal is to make it completely performance-oriented.

AUDIENCE QUESTION: How knowledgeable about EPSDT are the people who will use this preliminary draft, and are involved in its drafting?

MR. KOPPENHOEFER: They are primarily our Regional Office staff, and they're the folks who've been involved with the EPSDT program for the last couple of years. We have selected five people who are knowledgeable and experienced in the program, and are relying heavily on their advice and judgment. It won't be bureaucratic, and I don't think it will be ivory-tower-ish. We will provide you adequate time to furnish comments on it.

MR. HISCOCK: Our final panel focuses on management information needs at all levels, and on making improvements to information systems. Steve Leeds will moderate the panel discussion.

MR. LEEDS: Our Christmas party included the typical office humor show. One skit I thought outstanding was a guy doing a takeoff on Lily Tomlin in her character of Ernestine, the telephone operator. The best line "Ernestine" had was: "We're big government, and we don't have to care." That strikes a familiar note when talking about information systems and data sources. In all the public programs I've seen, information systems and data sources are among the sore subjects. One thing the Federal government does well is to confound State and local programs with information requirements. We're taking positive steps to overcome and change this situation. This panel will talk about some, but I'm going to talk briefly about one in particular before introducing the panel.

Our program has two Offices, one in Baltimore, and one in Washington, D.C. I'm in the Washington office, and at least three times a week we get a call from the American What's-Its-Name Association, concerned with a particular disease. They want to know how many Medicaid children have the disease, what services are provided to these kids, the costs and outcomes. My answer is, we simply don't know. We don't have that information. I think it does a disservice not to have it. Some information just doesn't exist. Although nice to know, some is unobtainable. We think some does exist, but don't know where it is, how to get it, who controls it. As we develop into a more comprehensive child health program we must try to develop more knowledge of these data sources. We're not necessarily going to collect it ourselves, but want to know where the data are, what it contains, and how to acquire it.

Therefore, this year we're going to put out a contract bid to learn about where these data sources are. We're going to focus explicitly on information sources that already exist. We're not attempting to develop new information sources, we're not asking States for additional information. We need to find out what Federal sources in other special projects exist, what kind of special and annual surveys there are. We want to get a good, comprehensive view.

The panel will discuss different aspects of management and information systems. Mary Abdalla, of our Office of Child Health, will talk about the HCFA-120 and HCFA-156 data collection tools. Nelson Berry from HCFA's Office of Methods and Systems will talk about the General Systems Design. Susan Fox from Professional Health Research in San Francisco will talk about using the GSD, and Vern Smith will comment on all that from the TAG and State view.

MS. ABDALLA: Having worked with the States, one of the more rewarding activities is seeing how the program actually evolves, meeting and the individuals who deal with problems daily, and seeing how the requirements we impose cause frustration, and understanding that frustration. I'd like to review some of the history of our reporting requirements. In the beginning we required only cursory information to get some idea of how many children were being seen, what percent of the Medicaid population was being served, and the conditions being reported. Those conditions were vision, hearing, and dental. We tried to collect some information on lead poisoning, and finally, we had a big category, other.

The report was to be divided by age group. We realized that initially it would be a burden on the States and Regions to collect it all, so we had a cutoff at zero to six, and a few months later added from six to 21. As Steve mentioned, we get many requests for program information from in and out of government: how many of your children have this disease or that, what impact is the program making, how many children are being treated, and so forth. We tried to collect some treatment data and found, to our dismay and enlightenment, that States often didn't have the capability to report treatment data. They could not link screening with treatment. We don't know unless you tell us exactly how much of a burden and a problem it is to you.

To improve the information base from the NCS 115, we began to restate what information we needed, resulting in the NCSS 120, which later became the HCFA 120. This requested similar information, but tried to get at treatment. That also proved unsatisfactory. We decided that information on conditions found was needed, and on initiation of treatment. We had some of that information from some of our demonstration projects. For example, one study demonstrated a 78 percent show-for-treatment rate for children screened. That effort led to the HCFA 156. We sent it out to the States and received quite a few comments that put us on the straight and narrow again, and made us see that much of the data, while it existed, was not collectible. We want to know why that is so.

We have issued Action Transmittal 81-2, limiting the information to be reported on the HCFA 156. Those data dealing with individual conditions are held in abeyance. Please understand that we are concerned with getting that kind of information because it is important. We have to compare where we've been and where we're going, and we have to plan for future program efforts and show impacts. We want to know, and be able to tell others, that the children we are serving are actually being treated. A good example came up yesterday. People asked Claire Meuller about the impact of promotion in terms of children getting services. Also, people wanted to know about private providers. Responses reflected being too busy to collect that data, although there must have been some impact. Sometimes we feel that same feeling, but the next time such a campaign is initiated, I hope we'll think that maybe we should prepare, and canvass providers to see if there was an impact. I think that's how it sometimes

happens at the Federal level, too. When the information comes in, we make incremental requests. We do appreciate the comments you give us on the requests we make and mandates we give. Otherwise, we're not going to know exactly how it impacts on you. I know you're not reluctant, but I want you to know that we welcome it.

Lastly, as Joy Morell and Dorothy Clarke said yesterday, we have to keep in mind that the business we're all about is seeing that children get adequate health care.

MR. BERRY: My name is Nelson Berry. I work in the Bureau of Program Operations, Office of Methods and Systems, Division of Systems Planning and Development. We have a functional responsibility to develop, design, direct and coordinate the systems, plans and studies related to Medicare and Medicaid. Currently, special emphasis is being given to the definition and development of portions of the MMIS: third-party liability, surveillance and utilization, long-term care, and eligibility. I'm here today to discuss the EPSDT portion.

We have developed two drafts of the General Systems Design, which were circulated for review. We received comments on the second draft from all Regions, four States within the Systems TAG, six States within the EPSDT TAG, the four internal divisions, the Office of Child Health, and a contractor for EPSDT with the Office of Child Health. The GSD is in final format now. It's awaiting clearances, with a proposed effective date of October 1981.

The objectives in the developmental process included a change in basic philosophy. We moved to a data-base concept. That means collection and retrieval of information, as opposed to data, related to the basic management of the EPSDT program. The system is integrated into the MMIS system, and addresses major management and operational requirements. We strive for accurate and timely information to manage the program and to provide services. We also made a conscientious effort to incorporate comments and recommendations we received.

The EPSDT subsystem is designed with the explicit purpose of meeting unique functional requirements found only in the EPSDT program, and specifically structured to be compatible with and complementary to the MMIS. The subsystem interfaces with three other subsystems of the MMIS: the recipient, the provider, and the claim processing subsystems. We designed it to establish and maintain identification of all individuals eligible for EPSDT services; establish automated procedures to support outreach and case management functions; provide documentation of services and actions taken, and to provide the ability to reproduce reports to ensure that services are being offered and received in a timely fashion, as specified by EPSDT program regulations and in the Quarterly Child Health Status Report. There are four major modules of the General Systems Design: case identification, to establish the case or recipient data

base; case management, to maintain data on the EPSDT-related services; case matching, to update the data base; and management reporting, to provide information to the user.

We have an integrated process which will perform the necessary functions to identify eligible clients, inform them of available services, track them through screening, diagnosis and treatment initiation, and produce required reports. I'd like to read the draft "Foreword" of the GSD to you, which sums it up.

> "This document represents Volume VI of the Medicaid Management Information System General Systems Design (MMIS GSD). This Volume describes the functional requirements which are needed to develop an automated system for the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, as specified in the 1967 Amendments to Title XIX (Medicaid) of the Social Security Act, and are further defined in 42 CFR Part 441.
>
> "The overall objective of Volume VI of the MMIS is to improve the capability of a State agency to administer the EPSDT program within the State through the use of automation. In order to accomplish this objective, emphasis has been placed on developing a GSD which will provide operational personnel with information on individual recipients,and will provide program management personnel with the summary information needed for planning, monitoring, and controlling the EPSDT program.
>
> "The Health Care Financing Administration's Bureau of Program Operations and Office of Special Programs view the EPSDT GSD as a vital instrument which is needed to help States satisfactorily meet their responsibility under the law.
>
> The General Systems Design in this EPSDT subsystem can be applied to any State or jurisdiction, regardless of the size and magnitude of the Title XIX program in effect.
>
> "The design, its functional requirements and objectives, also represents the criteria on which States are measured for conformance to receive the increased Federal financial matching for claims processing and information retrieval systems, as provided in Section 235 of Public Law 92-603."

I'll be glad to talk to you at any time regarding the EPSDT subsystem, or any other subsystem or system part of the MMIS. I will be here through the entire program to meet with you individually or collectively to discuss the GSD, give you any advice I can, personal observations, or whatever. I'm a Federal resource here, and my time is yours. However, I would like to ask that, outside of any interface we have here - and it's very important to us in our division, any interface with us be coordinated

with the Regional Office in your particular area. It makes life easier if you work through the Regional Office. If you write a letter, please copy the Regional Office.

MS. KAHLANDT: I'm Sandi Kahlandt, from Nebraska. If the county regulations, or a portion of the county regulations, are generated from blocks, what will that do to this General Systems Design? Will that be revised, or will it stay the same?

MR. BERRY: Sandi, as I envision it right now, it will not have an effect on it. If you will notice, in the Federal reporting area we say Federal reports include "reports required for documentation as specified in 42 CFR 441(b) and the Quarterly Child Health Status Report." So the GSD is saying you'll report in conformance with regulations, and that's it.

MS. KAHLANDT: But if that regulation is changed, that would have some effect on this....

MR. BERRY: Possibly, Sandi, but again, how can we work on what may be? We have to draw a line and work on what is, right now.

MS. KAHLANDT: But we have to be getting ready for such changes.

MR. BERRY: I'm aware of that, so that's got to be part of your planning process. My advice is to say, right now, this is where it stands. What did you distribute, Bill, an Action Transmittal that says "suppression of those lists." I don't know if those lists will ever be brought back You know, they may raise them, they may say, hey, don't suppress them any more, we want that data available. I have a problem answering you because I have to work with what is in effect right now and, personally, I think it will have very little impact if they do away with the penalty regulations.

MS. HUNT: Susan Hunt, from North Carolina. Since the GSD is going to incorporate reporting needs, what will that mean as far as the list? Because, when we make a systems change, we're going to put all our efforts in at once.

MR. HISCOCK: My only comment is that nothing is ever permanent. We cannot wait for perfection, because perfection never arrives. I'm not a systems person, but my observation is that in the GSD a structure is being developed to accommodate what local and State management requirements are. Some people call that flexibility. Yes it plays hob with design, but we have to be prepared for the dynamic world we live in. That means constant change.

MS. ABDALLA: The General Systems Design doesn't speak to specific diagnoses detailed under the HCFA 156. It doesn't even speak to the penalty regulation directly. What it allows you to do is to track kids through

the system, from informing through screening to treatment, whether it's done by one provider or a number of them, and it uses a claims-based process. That's the EPSDT program. Remember, 1905(a) says that everybody has to have available screening, diagnosis, and treatment, and that's not going to change unless it's decided not to have that kind of program at all. The GSD is quite general, simply allowing you to walk through to completion of treatment. That's what we're all concerned about. I think using the GSD should give people the ability to free up some of the labor-intensive activities. We're going to be as flexible as possible. Something could be equivalent or acceptable under the system, especially for those people who have up-and-coming systems, or already have something in place.

MR. LEEDS: Next, we'll hear from Susan Fox, of Professional Health Research.

DR. FOX: In California, we were faced with developing a design for the new EPSDT case management system while the GSD was itself being developed, so it was in flux. While the issues of whether lists would be required or not and what data would be required in the HCFA 156 were being debated, we've been looking at a system design that has to contend with this kind of change. It would be nice to start out with a systems design knowing exactly what the system is supposed to do, but in a large-scale project many things can happen. The benefit itself could change, the scope of services, the eligible population. The system has to be flexible enough to accommodate these changes. Certainly, if you have to go back in and make substantive changes over time, as in North Carolina, that can be detrimental.

Our California case management systems design project is an interesting joint venture. To begin with, the California Department of Health Services entered into a Memorandum of Understanding with the Office of Child Health, under which technical assistance is being provided to design an automated case management system which will meet California's particular needs and also be within the scope of the GSD. The Office of Child Health contracted with the National Institute for Advanced Studies, a Washington, D.C., consulting firm, which in turn subcontracted with my firm, PHR. The California project is one part of the central effort. In the other part, the Office of Child Health has visited three States: Iowa, Oklahoma, and Missouri. These States were selected because they had an operational case management system. After visiting the States, a generic model is going to be developed which describes the procedures that are used in those States. Under the California design may interest States currently trying to decide how to approach a case management system model for a large-scale, large-sized State whose program is State-supervised but county-administered.

We have a large and unusual team, comprised of the Office of Child Health and the Child Health and Disability Prevention Branch of the California

Department of Health Services. We also receive support from the Regional Office and from the Office of Methods and Systems. With this team, we have visited and interviewed about 300 people in California. We are charged with designing a case management system that can meet the General System Design standard. It has to be capable of integrating and interfacing with the great variety of existing operations in California and accommodating all this future change. First, the system has to work within the county welfare system. In California, there are 58 counties. Thirteen of them share a common system, but the others are all different, including Los Angeles. It has to integrate with a new Statewide Medicaid eligibility system which has not been implemented for all the counties. It has to accommodate the needs of the child health offices, most of which are operated by county health departments, but some of which are staffed directly by the State. It also has to interface with the State claims processing system operated by the Health Services Department. The screening claim includes both the screening assessment outcome data and serves as a billing document for the providers. In addition, the system has to interface with the State MMIS, which is operated by Computer Science Corporation,the fiscal agent for medical claims. There's also a separate contractor who processes the dental claims.

California also has very active Prepaid Health Plans (PHPs). The enrollment right now is in the neighborhood of 120,000, mostly AFDC. The PHPs have to provide a course of screening benefits and follow-up treatment and case management, although that function is shared with CHDP. There is a separate branch that produces the HCFA 120 report and does battle with the HCFA 156. The Systems Branch of the Department of Health Services produces automated periodicity notices to individuals over two years of age, and the EPSDT lists. So, throughout the State, if you could draw together all these pieces, we would have all the ingredients required for a basic case management system.

One other comment about California, because I'd like you to know what this model may be able to do for your State. There is an EPSDT program, but the State child health program covers a larger population. About 70,000 other children are covered under State funded sources other than the direct Medicaid program. Thus, there are a variety of different inputs from the Department of Social Services and Department of Health at both State and County levels.

The GSD for the EPSDT case management subsystem is described as a subsystem of the Medicaid Management Information System. That system is basically a vendor payment and claims data reporting system. It processes provider claims, and monitors the Medicaid program. However, in the basic MMIS there is no case management function. So this subsystem is very much different, requires an additional kind of processing and data collection from the rest of the MMIS. The basic change, of course, is that there's an intervention with clients directly, which does not occur in merely paying Medicaid bills. Our task is to try

to fit this kind of system into the MMIS. Now, the MMIS has valuable information, the case management system couldn't exist without being a part of the MMIS. The MMIS will supply the eligibility information needed to identify individuals eligible for services. The claims history files will provide the treatment and diagnosis information. In addition to any existing source of data, such as eligibility and claims history, a system like this must have some ability to accept input of data from the case managers, who are the source of contact with the clients.

We have followed a standard systems development approach. We first documented the current State processes. If you were to document precisely all of the actions that go on in order to support case management without having an automated system, you would see that there are thousands of minute steps required for recordkeeping and logging. The GSD would automate much of this, but not all recordkeeping is appropriate to automation. The second step was to develop a requirements document that illustrated what the system ought to do. When we interviewed the county and State staff we always asked the questions: would you collect this data if it were not for the regulations? What data would you collect in addition to that data required by the regulations? We tried to get a picture of information that would be important to the system that wasn't limited to responding to regulations which could go away.

From this process we developed a set of system alternatives which has yet to be resolved. The project will also produce a feasibility study for the State budget process, and advance planning document to secure Federal matching funds, system specifications, an implementation plan, and the training package. During the course of the project, several important policy issues arose that are related to the system design. In the design of the systems you're asking the questions: should this function be automated? If the function gives you this capability, would you want to use it or not? Some of these are interesting issues. I've developed a report that takes the four modules of the GSD which Nelson just described: the identification, case management and case matching modules, bringing screening and treatment data together, and the reporting module. I'd like to hand out this package, which is designed so that you, as a State, can respond.

In the case identification module, an issue you will encounter is determining the size of a master file. Within EPSDT there are some considerations. In California, size is of significance, because it can approach two million. Also, how long should an individual remain in the file? That could extend the two million to five or six million over a few years' time. It will help us to know what other States feel about what population ought to be covered by this case management system. You'll notice that AFDC eligibles, regard less of their response, are listed as an option. The system could be designed so that it would only track those people who had initially said they were interested. That would be the smallest size case management file for EPSDT.

Going up the scale, should it include all eligibles for the benefit, regardless of responses to the offer of services? If your State has a prepaid health plan, would you want those individuals to be in the file? Or do you consider that the prepaid health plan is structured so that it could do its own case management without being part of the State's master file? If your State does cover children beyond Medicaid-eligibles, would those children be included in the master file? The case management module client tracking portion of the system is related to the first question: which client should be tracked in an automated system? This is a bigger question than it may appear to be. It means, for how many clients will some case manager be interacting with the system, supplying information and getting information back? Should any or all of these different categories of clients be included in the case management system?

We would be interested to know, from those States that currently operate a case management system, which clients are currently tracked. We know that all States are tracking all clients they're supposed to be tracking. The question here is asked in the context of the automated case management system. In how many categories should the client be tracked? How much information would you want an automated system to actually record and make available to you? Would it be every single action a case manager performs on behalf of a client, every phone call, letter, and response? Or would it be limited to certain significant events, like verification that screening had occured, or that treatment had been initiated? Just to support the basic case management system in a manual mode requires considerable paperwork, piles of paper stored and filed in logs and records, roomsful of paper. Should the system do away with all paper? Are there some procedures better kept by manual recording?

The third module, case matching, is actually the most controversial. It is probably the most difficult portion of the case management system to implement, because the EPSDT subsystem is being born several years after the other MMIS subsystems. If it had been anticipated that case management functions were to be included in MMIS, that could have been part of the picture from the very beginning. Now we're trying to squeeze in this capability, and there is some friction in doing it. It's not impossible, but there are some rough edges. The issue we're struggling with is, can an absolute match be made between an open screening condition (like vision or hearing) identified in the screening process, coded on the assessment form, saying followup is required, and the initiation of further diagnosis and treatment? It is not too difficult in the MMIS context to make a match between a screening claim with a client's name and date of screening on it and a treatment claim with some corresponding date of service. That linkage can be made. But to make this match closer, to close out a condition and say, with a sigh of relief: this condition that was identified is now being treated, the child is in treatment for that condition - how can we do this?

The first possibility here is the match should be made between a diagnosis code on the screening document and a range of related diagnoses coded on treatment claims. This would not be easy to do in California. Perhaps the screening physician cannot supply a diagnosis code. We're asking, is this a viable approach? In your State, would you want to do it that way? Another alternative is, could the match be between a condition code and then with a specified range of diagnosis codes and/or procedure codes and/or the provider type and/or the physician's specialty on the treatment code? This item is quite a struggle, California is interested in being more precise in this kind of matching capability, but has to decide on how close to come, even with large computer resources available.

As for the reporting module, if you were designing a system that met your needs in managing the program from scratch, what data would you think most important to two basic levels of information? Think of what information the local case manager has to have, and what the State administration has to have. At the Statewide adminstrative level, as opposed to the case manager level, what data elements are necessary? If you did not have to produce the HCFA 120 and HCFA 156, would you still do so because some of the data on those reports is valuable? If so, identify that data.

The project in California is due for completion in October 1981, the same October the GSD is supposed to be finished. Nothing we have come up with so far is in conflict with the various stages of the GSD. It appears general enough so that if the system designed meets California needs and keeps the general GSD principles in mind, we appear to be on the right track. From this morning's presentation, it occurs to me that the assessment plan for EPSDT would be important, so that data will be collected at the appropriate points to facilitate assessment.

A final comment. In an age of such flux, because the case management system is being interfaced with many other systems, the intricacy of these programs, and the different kinds of providers and clients, the system has to be flexible. If you're undertaking the design of the case management system, it is important to think of all the important data to collect, for whatever purpose, and try to develop a design that will guarantee that a range of data is collected, regardless of what kinds of reports will be requested.

One way of looking at this is that a fixed report, no matter how onerous, is at least something you know is there. There are often inquiries from the legislature and other sources demanding information instantly. The system ought to be able to anticipate current and future requirements, information that can be requested by local case managers, the State legislature, OCH, and the person who calls up and asks how many children do you serve who have such-and-such an illness? That's a lot to bite off in the design, but it's a good starting point to have the universe in mind. Then you can start in making your system design flexible, by saying, as of right now we cannot accommodate this additional source of

information, but we know that it could be important at some time, and so we've made provision for it. We may not build it in at the moment, but we won't do anything to eliminate it.

MR. LEEDS: Thank you, Susan. Vern Smith, TAG Chairman, will close the panel discussion.

DR. SMITH: When Regina McPhillips called and asked if I would serve on this panel, I objected strenuously, indicating that any other panel would be fine, but not this one. I am not a systems person, and I feel singularly inadequate to respond to some of the detail that's been discussed today. However, I will do my best to respond with some observations from my own perspective in dealing with States.

My first observation is: much of what is being required of the States seems to assume the States are unwilling or unable to provide information unless forced to do so. It's my observation that States are not reluctant to provide information for themselves, for their own management, planning and evaluation purposes, for responding to people to whom they report at the State level, their bosses, the legislature, and so on, who want to know the effectiveness of the programs going on at the State level. I think States sense their own interest in having an adequate and appropriate data base in order to track, assess, and evaluate, know what's going on, and be able to justify it to people in the State.

One has to ask: Who is really running the program? Who is responsible for EPSDT? Who are the program managers for EPSDT? I think if you look, you'll find the responsibility for running an EPSDT program is at the State level. That is where ultimate responsibility for delivering the service lies. This is the orientation of the people delivering the service; we are at the State level, delivering the service. Superimposed on what we're doing at the State level are some sophisticated data requirements. These are suggested to, in some cases required of, us in order to meet requirements perceived at the Federal level. The problem is that the State programs are all unique, every State is different. We have county-administered, State-supervised; State administered, large and small; States that have a tradition of dealing with automation and have had MMIS for almost ten years; some that are not yet MMIS-certified; all with differing ways of delivering service and different mixes of providers. Within this environment we have a GSD requirement intended to serve the purpose of every State, and it's very difficult for a single GSD to meet the needs of every State. Nelson mentioned that input had been received from the States and various TAGs; systems and EPSDT TAGs and so on. Nelson didn't mention it, but the systems TAGs I think, has actually endorsed the GSD.

MR. BERRY: Yes, they have.

DR. SMITH: Even in the EPSDT TAG, which I think has more of a program orientation than a systems orientation, and is less taken by what I might characterize as the seductive allure of all this nifty data-gathering apparatus and machinery, it's been difficult to achieve consensus as to the effect and purpose of the GSD. New Jersey and Minnesota are two States represented on the TAG and, to quote Nancy Feldman of Minnesota, "I still feel the draft GSD is far too general to be of much use to the States." On the other hand, Tom Russo, the Director of the Medicaid Program in New Jersey, wrote: "One of our fundamental concerns with this GSD is that, instead of stating the requirements in terms of objectives to be met, the GSD has specified in so much detail as to precise data items, data structure, and report formats, that States which have already developed and installed functionally comparable systems with which to support their operation of EPSDT may be heavily penalized for their trouble by now being required to make numerous unneccessary changes merely to conform with nonessential details of the GSD."

Part of the problem we're facing is that EPSDT is not even a formal system across all of the States. Many States have already gone a long way toward developing systems which meet their unique requirements in the way their program has developed in their own individual circumstances. I sense sometimes that we have a legitimate need for data. I sympathize with the problem Nelson has had to face, but I also sense that we have a very big tail, sometimes, that's wagging the dog. You have to keep the perspective that EPSDT is part of Medicaid, and we have this large tail, the systems side, which is directing the way this dog is going. In any case, the GSD is coming. It's there, like a freight train coming down the track, and I think we all need to be aware of it. There are some questions we have, some specifics we're still more than a little concerned about, such as how the GSD is going to impact in our State. I talked with our systems people before we left, and believe the GSD is generally compatible with our own systems and that we can probably live with it. That doesn't mean we don't have problems with it, we do. There are a couple of specific problems which I think bear mentioning. Some time ago, Nancy Feldman wrote in a letter: "Although the turnaround system in which local workers input information on specific EPSDT cases into the system looks good on paper, our experience has been that such a system is very difficult and expensive to implement and run with accuracy." I think this summarizes a key concern, and that is that the system can require additional effort at the local level, inputting transactions, various sorts of case changes and so on, at the local level. It can generate a lot of reports and a lot of paper. The question is, will it be useful?

CHILDREN AND THE FEDERAL BUDGET: ENDURING PRINCIPLES FOR CHILD HEALTH ADVOCACY IN THE '80s

Sara Rosenbaum, J.D.

It is a great privilege to be able to speak with you today. I have known many of you through letters and telephone conversations, so it is nice to finally have the opportunity to meet you in person.

I would like to keep my remarks brief, so that we can discuss the topic that I inevitably would be addressing you about today: the crisis in health care that looms before us in light of the tremendous budget cuts proposed by the Reagan Administration. All of us in this room have labored for years to implement a program that may well not exist at all by the end of this year, either in its current or an equivalent form - the Medicaid EPSDT program. We must work together to assure that the cause of child health is not lost.

Let me tell you first a little about the Children's Defense Fund (CDF). CDF is a national public charity created in 1973 to provide long-range and thoughtful advocacy on the major issues that affect disadvantaged and minority children, including health, education, child welfare, day care, and juvenile justice. Over the years, we have prepared lengthy reports about the major programs affecting children and have worked extensively with Congress and the Department of Health and Human Services to expand or improve on those programs.

With respect to health, we have done three major studies: Doctors and Dollars Are Not Enough, which provides an overview of the major health problems affecting children and cites examples of successful child health projects; EPSDT: Does It Spell Health Care For Poor Children?, which explores the achievements and problems of the largest Federal health program for poor children; and A Study of the Title V MCH and CC Programs. Our work, along with the work of others, formed the basis of the proposed Child Health Assurance Act (CHAP), which would have corrected many of Medicaid's greatest eligibility and benefit inequities for children, and would have provided States with substantially expanded Federal assistance to meet children's health needs. As you know, CHAP failed in the last days of Congress, as reform efforts halted in the face of a new incoming Administration.

Today, we at CDF no longer have the luxury of carrying on major reform legislation. Today, we and you are fighting to hold our ground in the face of extraordinary budget cuts that would cap Federal Medicaid expenditures at some 25-40 percent below projected 1982 expenditures, wipe out the Medicaid entitlement, allow States to drop the special EPSDT package, and totally abolish the Title V program (perhaps our nation's most time-honored commitment to the cause of maternal and child health).

There is no doubt that these efforts will harm the "truly needy." Mothers and children who are eligible for Medicaid and Title V are, by definition, the poorest and most high-risk members of our society. Without Medicaid cards and Title V-funded health clinics, we fear that the clock will be turned back 20 years for these families - back to the days when children were routinely delivered in hospital parking lots because their mothers had no way to pay for hospitalization - back to the time when children routinely went unimmunized against major childhood diseases - back to the time when eyeglasses, dental care, treatment for strep throat, and other fundamental health care was a privilege, rather than a right.

As I speak to you now, the Senate and House are deciding how much money to save and how these savings are to be accomplished. There is every likelihood that the savings will come on the backs of mothers and children in the form of Medicaid, AFDC, and nutrition cuts that are positively life-threatening in their magnitude. These cuts will undo years of painful, thankless work to make already bare-bones programs stretch to meet human needs. Currently, nearly 30 States have stated their intentions to make drastic Medicaid cuts, including elimination of all optional Medicaid services, caps on hospital care that will leave 30 percent of all high-risk infants hospitalized in Baltimore without adequate health insurance to pay for their stay, and reductions in provider reimbursement that make it impossible for clinics and doctors to treat Medicaid children.

As we began our advocacy, we had to develop a set of fundamental principles that would guide us in our work. We had to engage in the impossible task of determining what mothers and children could do without, and we had to come up with humane ways to save money. I would like to share these principles with you and discuss what you can do to help.

What Do Children Need?

We believe that if children's health care needs are to continue to be adequately met, certain essential health services must be provided:

1. Health Insurance. The Medicaid program must continue as an entitlement program so that poor children continue to have health insurance for essential health services. Imagine how much more complicated your task will become if children under your care suddenly have no way to pay for expensive diagnostic and treatment services. Even if public health departments and community-based clinics had enough funds to provide basic health services, what would we do for the child who has a need for treatment for chronic or episodic illnesses? Our goal of linking poor children with a comprehensive and continuing health care system will be next to impossible to achieve if millions of low-income children are left without health insurance.

2. Supportive Services. We know that children are underutilizers of basic health services. They frequently come from families who live in such constant crisis conditions that getting basic health care is a luxury.

   We must develop some way to educate families about prevention, and help them get care in a timely and humane fashion. We have to think about creative outreach, such as visits by hospital nurses to mothers of newborns, speaking informally to Head Start parents, and making sure that when a child goes to a clinic, someone takes a moment to talk to his or her parent about putting the child onto a regular course of preventive care. You all know your States best, have studied poor families' patterns of health care utilization, and have ideas about how to reach families. We urge a continued commitment to an enriched outreach program that meets State needs.

   As important as outreach is assistance with transportation and scheduling. Scheduling and transportation are critically important, since most poor families are new to routine health care, and need help finding physicians and dentists.

3. Adequate and Appropriate Providers. Even with affirmative outreach efforts, we know that the vast majority of children do not hook up with health care the way a family hooks up with a box of detergent in a grocery store. Families go to get help when they need it. Therefore, we must continue to have adquate resources to make sure that when a child comes to a health or hospital clinic or visits a physician, that child get, in addition to treatment for a specific illness, a thorough exam and support assistance.

   After spending years working with disadvantaged families, I am absolutely convinced that we must be prepared to respond to their health care utilization patterns, and try to make their episodic encounters with the health care system as fruitful as possible.

4. An Authority for Maternal and Child Health (MCH): With Funds to Plan, Develop, and Staff Necessary Health Services and to Speak for MCH Needs. One of mothers' and children's most fundamental nees is a Statewide authority that can assess needs, develop health resources, and work with EPSDT administration to make the best utilization of existing services. The Title V MCH program now provides the basis for such and authority. Many EPSDLT children rely heavily on Title V MCH and CC clinics for their services. Many families benefit profoundly from the work of community and school nurses who act as advocates for their needs as well as providing health care. Their service must continue.

Saving Funds in a Humane Fashion

In order to preserve adequate funding levels to achieve these goals for mothers and children, we believe that Congress whould consider financing reform handles that work to control the high cost of institutional care while encouraging the utilization of preventive services. These handles might include:

- o Reforming the retrospective cost methodology which is currently used to reimburse hospitals under Medicare and Medicaid, and allow States and the Federal government to negotiate prospective fees.

- o Increasing Federal funds for State expenditures on ambulatory services, including clinics and physician visits.

- o Increasing the reimbursement rates which States provide to physicians.

- o Prohibiting cost-sharing for non-institutional services, since co-payments often discourage beneficiaries from seeking care until costly institutionalization is required.

Conclusion

We have a long road to travel this year if we are going to do the type of advocacy that children need. I hope that we can all work together to preserve decades of progress.

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